

THE MEANING OF SOCIAL SUPPORT;
A DESCRIPTIVE STUDY OF INFORMAL NETWORKS AND
OF HEALTH VISITORS' FORMAL ROLE IN SUPPORTING
THE IDENTITY OF WOMEN WITH BREAST CANCER

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I declare that the work reported in this thesis was composed and conducted by myself.
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Abstract of Thesis

This thesis emerged from the writer's experience in nursing education and her clinical involvement with patients with breast cancer. Its essence is to explore perceptions of the meaning of social support, a concept which has been loosely used in previous sociological, nursing and breast cancer research and by practitioners. Grounded theory was adapted to retrospectively analyse the writer's previous research interviews with patients with breast cancer. Discourse analysis of patients' and health visitors' interview transcripts examined the language they used to symbolise social support and lack of support. Diagrams of patients' social networks drawn by patients and health visitors, illustrated their perceptions of support and strain and increased research reliability by confirming patients' interview statements or producing additional data. Patients' and health visitors' network diagrams were compared. The research findings have implications for (1) sociological theory, (2) breast cancer care and (3) nursing.

1 Sociology

The main theme connecting patients' problems was the threat to their identities from breast cancer. Respondents perceived social support to be actions/attitudes from formal or informal sources which maintained their established identities or assisted changes to their identities. They identified seven types of informal support.

Respondents constructed support for their changing self perceptions by reactivating relationships with people who had recovered from breast cancer. Most also formed new supportive relationships, especially with peers. Respondents reciprocated support they received by early resumption of their family roles, by protecting network members from stress associated with their illness and by offering support to others. Most stress to patients resulted from network members perceiving the women's illness as threatening aspects of their own identities. A few relationships were lost altogether.

Quantity of relationships was important to respondents because they sought a variety of support types. Quality of relationships (closeness) was also important in

maintaining key aspects of respondents' identities. Close involvement of health visitors with some respondents limited the extent of their support.

2 Breast cancer care

Respondents faced 6 identity crises and had to move through these crises towards recovery, re-evaluating themselves and accepting changes in identity. Failure to cope meant that women's identities remained under threat and the crisis was unresolved. Support was ineffective if given after a crisis had passed. During crisis points, respondents needed both formal and informal support to avoid negative and encourage positive self concepts.

3 Nursing

Appraisal support was a distinguishing aspect of professional support, helping patients to continually assess their situations. Respondents' coping ability was increased by the availability of health visitors who had an important role in building up their identities. Nurses promoted respondents' informal support by assessing their support needs, preserving existing support and encouraging further informal support. Nurses must increase their skills in building up clients' identities and avoid practices which undermine these identities.

PREFACE

This thesis aims to make a contribution to the understanding of the concept of social support.

Background to the present research - The Macmillan Project

In 1989, Dr Alison Tierney, Director of The Nursing Research Unit, Edinburgh University, obtained funding from the Cancer Relief Macmillan Fund for a three year project to promote research based practice in breast cancer nursing. This project is henceforth referred to as the Macmillan Study. Based in the Nursing Research Unit, the clinical base was the specialist Breast Unit, initially at Longmore Hospital and now at the Western General Hospital, Edinburgh. I was appointed as Research Associate to conduct this study. In a joint decision with nursing staff from the Breast Unit, I decided to conduct research into the support by health visitors of patients receiving treatment in the community for breast cancer. There was a liaison health visiting service in operation at the Breast Unit, the effectiveness of which had never been evaluated. The Macmillan Study focussed on what support health visitors provided at various stages in the lifetime of the disease and the nature and value of the support as perceived by patients. The views of health visitors on the effectiveness of their support, and on the adequacy of their preparation for this role were also explored. Both qualitative and quantitative methods were used. All subjects in this study were having treatment for breast cancer. Some patients had advanced breast cancer or recurrence.

Choice of research subject

From the Macmillan Study, I developed an interest in the concept of social support. During my interviews with women with breast cancer, they often mentioned the various types of support they received during their illness but without clearly defining what such support meant to them in relation to their needs and how they perceived their own role as recipients and givers of support. A lot of data were available from the Macmillan Study on perceptions of social support by patients and health visitors.

During the Macmillan Study, I examined psychosocial and nursing literature on social support, breast cancer, and methodology. I became aware of the ambiguities involved in the concept of 'support'. The literature often failed to define it and spoke of it in terms of the quantity of supportive relationships or content, for example, emotional or practical, without exploring its underlying nature or its intrinsic meaning or significance for recipients.

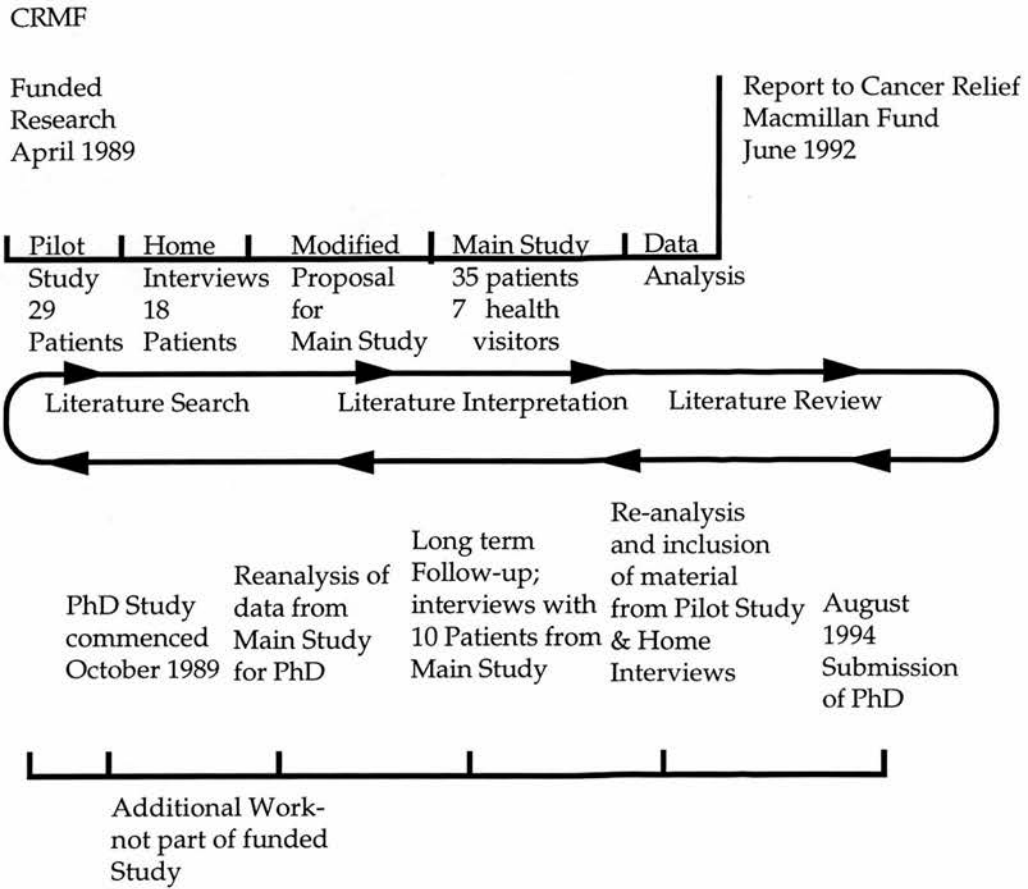
I was challenged to explore further the intrinsic meaning of social support, and its patterns during illness. A secondary question focussed on how formal support, particularly from health visitors, complemented the informal support patients received from family, friends and fellow patients. I felt that further research would provide valuable information on the interactions, and relationships which patients with breast cancer perceived to be supportive and the kinds of support sought from professional and informal sources at different stages of illness and treatment.

I noted some previous literature and research definitions of social support and methods of measuring it. My personal interest in sociology determined that a qualitative approach was the most appropriate means of exploring the concept. I used this approach to develop theory from both the literature and from the Macmillan Study data. The approach is described in the methodology chapter.

Social support measured through quantity and quality of relationships has been shown to be important to health outcomes. Other research has shown that separation from a loved person through divorce or death is associated with subsequent morbidity. Nurses need to have a greater understanding of the nature of the support which can be provided by informal sources and the circumstances in which it is manifested. Thus both formal (professional) and informal support complement each other more effectively and patients benefit. Few studies have explored the complementary roles of formal and informal support. This has been noted to be an important area for investigation (Nolan and Grant 1989). The purpose of the Macmillan Study was to explore what health visitors knew about supporting patients with breast cancer, how they used their knowledge and what difference they made to patients' coping ability. In this thesis, the focus shifts away from health visitors' caring role to exploration of the concept of social support as viewed from the perspective of both patients and health visitors.

The timetable for the Macmillan Study and PhD is presented in Figure 1.

Figure 1 Timetable for the Macmillan Study and Plan



Development of method of data analysis and of dealing with the literature

Introduction

Breast cancer is the commonest type of cancer among women in the Western world, accounting for 20% of all new cases. It is estimated that 1 in 12 such women will develop it at some time in life. Each year in the UK, 24,500 women are newly diagnosed with the disease and 15,000 die. For women aged 25-54 years, it is the leading cause of death (Baum *et al.* 1991).

Until recently, mastectomy was the preferred treatment for breast cancer. However, local excision is often now an option with adjuvant therapy being an important part of initial management. Treatment options include radiotherapy, chemotherapy and hormone therapy.

There is evidence that physical, psychological and sexual morbidity can accompany diagnosis and treatment of breast cancer. Research shows that after mastectomy, many patients developed psychological problems such as severe anxiety or clinical depression, requiring psychiatric treatment (Maguire *et al.* 1978, Morris *et al.* 1977). Surgeons hoped that breast conserving techniques followed by adjuvant treatment would reduce the incidence of psychiatric morbidity. However, while studies comparing the psychosocial outcome of mastectomy with lumpectomy and radiotherapy revealed some advantage to women treated by breast conservation in terms of body image, there was little difference in terms of psychiatric morbidity or sexual dysfunction (Fallowfield 1991). Tait (1988) noted that, regardless of treatment, 20-40% of patients with breast cancer suffered from depression, anxiety or sexual problems within a year of surgery, although such problems were rarely recognised by their carers. Failure to adapt to changed body image, compounded by prosthesis problems and anxiety about possible cancer recurrence are persistent research findings. Ongoing stress affecting patients with breast cancer is noted by Burish and Lyles (1983) who found that patients may take a year to regain normal function after suffering depression, anxiety and reduced self esteem. Other problems were disturbed marital relationships and physical after-effects of surgery, such as lymphoedema and frozen shoulder.

1 Social support-research questions

The Macmillan Study explored perceived needs of patients with breast cancer for health visiting support, recognising that they would be receiving adjuvant treatment in the community and that it was here that interventions to reduce stress would be needed.

I received evidence of morbidity accompanying diagnosis and treatment of breast cancer at an early stage of my research when I attended a follow-up breast clinic and noted a number of problems among 8 of the 20 patients seen by one doctor. Problems included recurrent breast lumps, lymphoedema of the arm, frozen shoulder, vaginal thrush, depression and dissatisfaction with a prosthesis. An interview with a patient who had had breast surgery three years previously showed clearly that such problems could persist over several years. However, she now thought about her breast cancer only fleetingly, whereas formerly, she had been preoccupied with it '23 hours a day'.

Evidence of patients' problems from literature and my own research convinced me that appropriate support for these patients was vital. However, although the problems of patients have been studied extensively and are well known, research on the most appropriate forms of support for these patients has produced more ambivalent results. I felt that a study of both formal and informal support for women with breast cancer would produce useful insights into the nature of support which would be relevant to this patient group and to givers and recipients of support in other situations. There would also be opportunities to observe how formal and informal support interacted. Initially, I wanted to explore six questions relating to social support;

- 1 What is the essence of social support?
- 2 How does it promote well-being in recipients?
- 3 How is social support constructed?
- 4 What are the conditions under which social support is given and received?
- 5 What are the roles of formal (nursing) and informal support in illness?
- 6 How do these two types of support complement each other?

I decided to study the meaning of support from three viewpoints, sociological, breast cancer care and nursing.

2 Sociological theories of social support

I hoped that sociological theories on social interaction, social networks and formal and informal relationships would provide insights into the concept of support. Sociological questions were

How can social support be defined in sociological terms?

What do people's social networks reveal about support processes?

How does the nature of professional and informal relationships influence recipients' perceptions of support?

2a Sociological definitions of social support

Social support has often been ill-defined in sociological research. Its apparent obviousness may be a major reason for inadequate theoretical work in this area. Definitions have been inferred from ways in which the concept was operationalised.

Quantity of relationships

Quality of relationships

Availability (likelihood of having someone there when needed)

Satisfaction with support

Types of support (manifestations).

Use of support resources.

In a review of social support research, Brownell and Shumaker (1984) maintained;

... we must understand how social support operates in order to determine in what context, for what types of problems and for whom social support interventions are appropriate. p. 5

They argued that in research into the effects of social support on health, predictive validity had been emphasised while construct validity had been neglected. They noted three consequences of this. Disparate methods were used to assess the effects of social support, limiting efforts to integrate research findings meaningfully. Taxonomies generated to capture the complex nature of support were expanding and risked including all aspects of interpersonal transactions, thereby obscuring what was uniquely support. Finally, critical conceptual gaps needed to be addressed before empirical methods were improved and a theory of support developed.

2b Content of support

Much research explores content of support or types of support given, for example, feedback guidance, information, intimacy, money and practical help with tasks. Some researchers have grouped these support types, for example, emotional support, material support.

2c Functions or purposes of support

According to most support models, support's overall function is to enhance recipients' physical and mental well-being. However, there are few models indicating how this is achieved. One such model was that of Shumaker and Brownell (1984). Among the health sustaining functions of support, they included self-identity maintenance and self-esteem enhancement. If stress is present, support could broaden the individual's interpretation of a threatening event and promote clearer understanding. It could also broaden the number of coping options. A criticism of this model is that identity maintenance would seem to be equally important in times of stress.

2d Negative or mixed interactions

Much social support research has neglected to explore the negative or mixed interactions occurring in most social networks. Such interactions could help in defining social support by describing what it is not. Patients' negative statements about attitudes and behaviour of some network members towards them reveal the support for which they had hoped. Shumaker and Brownell (1984) maintained that distinctions should be also made between interactions that were intentionally or unintentionally harmful and those that seemed harmful but were beneficial.

2e Conditions for giving and receiving social support

In social support literature, its functions are often confused with conditions under which it is given. Perceptions of both providers and recipients will influence whether exchanged resources are supportive.

I wanted to find out more about conditions under which support is given and received, for example, whether patients' attitudes and actions influenced the amount and type of received social support, whether patients were active in constructing their own support?

Theorists have suggested that, as people belong to social networks characterised by mutual obligations, 'exchange' models are relevant to support. Gouldner (1960) posited that people usually return benefits received from others and Shumaker and Brownell (1984) maintained that if people felt unable to return a benefit, they might be less likely to seek or accept assistance. If reciprocity was prevented then relationships between providers and recipients might diminish. However, the exchange model neglects the part of altruistic motivation in social support. Supportive resources exchanged between individuals may be grossly unequal as in the situation of a mother caring for a severely handicapped, unresponsive child.

I wanted to find out whether patients felt a need to reciprocate support received from their network members. Professional carers do not usually expect reciprocity to the same degree as informal helpers. Was this aspect of professional support in any way beneficial to patients with breast cancer?

2f Effects of support on the provider

The literature on 'burn out' focuses on costs experienced by formal support providers. However, informal support providers may also 'burn out'. Kessler and McLeod (1985) found that women were more likely than men to respond to the needs of others and to be involved as supporters in crises. They concluded that this emotional cost of caring accounts for a substantial part of the mental health disadvantage of women. Stress in the lives of others can increase providers' sense of personal vulnerability and they can become more aware of risks that exist in their own lives.

In relation to my own research, I hoped to explore costs incurred by health visitors in supporting patients with breast cancer. I also wanted to find out whether the breast cancer diagnosis increased feelings of vulnerability in patients' network members and if this affected the quality of support they gave?

3 Breast cancer care

As I was studying the concept of social support in the context of women with breast cancer, I was interested in their perceptions of the nature of support and how it promoted their well-being. Three questions seemed relevant;

- 1 What did respondents perceive to be their main problems since diagnosis?

- 2 What were respondents' perceptions of the nature of support (formal and informal)?
- 3 How did it alleviate their problems/promote their well-being?

3a Problems of women with breast cancer

Macmillan Study findings endorsed previous reports of a significant incidence of physical and psychosocial problems in women having treatment for breast cancer. Respondents' medical problems were usually related to treatment but, in cases of advanced breast cancer, also to disease. The main psychological problems identified were fears of recurrence and concerns about body image and sexuality. Many social problems were identified. I now wanted to find out how respondents perceived social support alleviating these problems.

3b Perceptions of support among women with breast cancer

While breast cancer literature has demonstrated the frequency of problems in women having treatment for the disease, it has been less successfully indicated how support could alleviate the problems.

Informal support seems to be important in this respect. Research has shown that support from the family had direct effects on coping with breast cancer and indirect effects on adjustment (Bloom 1982). Survival in women with breast cancer was significantly affected by the number of supportive friends and the size of their social networks (Waxler-Morrison *et al.* 1991). Regular contact between fellow patients decreased negative feelings and increased self esteem (Van den Borne *et al.* 1987).

The literature on professional support for patients with breast cancer has been more concerned with its outcomes than functions and content. It is not surprising that outcomes have sometimes been ambivalent. There is debate about the benefits to patients of their involvement in treatment decisions. The content of the professional support to patients involved in such decisions needs to be further explored. Fentman (1985) noted that giving a patient a choice of treatment constitutes support only if a great deal of information and discussion is available. If not, choice of treatment is just an added burden. There is also debate about the effectiveness of nurses counselling these patients. Maguire *et al.* (1980) found that 'counselling' of patients with mastectomy by a specialist nurse appeared to speed up their

adjustment but failed to prevent psychiatric morbidity. However, the content of counselling was not described.

The Macmillan Study had mainly explored women's perceptions of health visitors' support. I wanted to reanalyse my data to find out more about patients' perceptions of informal support from their network members. How did formal and informal support contribute to their well-being?

4 Nursing and health visiting

Support is a term used frequently in nursing but not often clearly defined. The question 'What do nurses need to do to give support to their patients?' cannot therefore be adequately answered. Questions relevant to support in nursing were;

- 1 What is the meaning of the concept of support in nursing?
- 2 How can nurses best support patients with breast cancer?
- 3 What is the nurses' role in building up patients' informal support?
- 4 What are the respective roles of formal and informal support at different stages of illness?

4a Meaning of the concept of support in nursing

In nursing, we use words like counselling, reassurance, autonomy and stress in a general way. These terms should be used more specifically to inform practice. Much nursing research has not explored the intrinsic meaning of social support and the processes by which it operates. It is difficult, therefore, for nurses to assess which interactions are supportive in maintaining health and promoting recovery from illness or to plan their support in a specific way. Roberts (1988) noted that

Often the diagnostic category used is 'lack of support'. ... it is clear that this diagnosis is too broad to lend itself to specific interventions. Part of the clinical and research dilemma prior to developing interventions, therefore, is to specify the various subcategories within this broad category that may lead to similar interventions. p. 6

Norbeck (1981) recommended that researchers should add to the predictive power of social support in the stress-social support-health models. An important way of doing this is to develop a greater awareness of what is meant by the term 'lack of support'.

Many studies have been conducted into communications between nurses, patients and relatives. In Whyte's (1989) research with families with a child with cystic fibrosis, aspects of professional support mentioned by parents as helpful were;

- 1 Information giving
- 2 Explaining investigations
- 3 Answering questions
- 4 Listening
- 5 Providing a link between clinic, home and school
- 6 Providing help with child care

Support in nursing has often been equated with 'counselling'. Yet counselling is a specific kind of support which may be appropriate in some aspects of nursing care but not in others. Egan (1990) described his approach to counselling.

The problem management and opportunity development model ... is not something that helpers do to clients; it is a process that helpers and clients work through together. It is the clients who achieve the goals of helping through the facilitation of the helper. p. 8

This approach is obviously appropriate in situations where there are opportunities for patients to make decisions for example, about alternative treatments. In other situations, patients may need mainly informational and practical support?

4b What are the respective roles of formal (nursing) and informal support at different stages of illness?

Most people require help from professional and informal sources during illness. Nurses need to know when and in what ways nursing and informal support are important to their patients. They need to know how their own input can be used to best effect. I wanted to know whether the timing of support was important for the well-being of women with breast cancer and if so, when formal and informal support were most appropriate.

In the literature, formal support is usually identified with crisis support. In crises, informal support may be inadequate because professional knowledge and expertise is required or support would impose too great a strain on the informal network. Informal support is identified in the literature with everyday support and meets many important needs which cannot be met by formal support. The problems of women with breast cancer and the need for both professional and informal support

have been well documented. Formal support is important at times of transition, at diagnosis, during treatment, on hospital discharge, at recurrence, during terminal illness. Informal support, for example, experiential support from peers, helps coping. Counselling services for the bereaved have been in existence for a number of years and can provide insight into the appropriateness and effectiveness of formal and informal support systems. Parkes (1980) reviewed the effects of different bereavement services. He found evidence to suggest that professional bereavement services (Raphael 1977, Gerber *et al.* 1975) professionally supported voluntary services (Parkes 1979) and self help services (Vachon *et al.* 1980) were all capable of reducing the risk of psychiatric and psychosomatic disorders resulting from bereavement. These forms of support were most beneficial among bereaved people who perceived their families to be unsupportive or who were thought to be at risk for other reasons.

Earlier I noted literature indicating that support had health sustaining and stress reducing functions. However, the appropriateness of formal and informal support interventions at different stages of illness has not been much researched. I wanted to explore this further. Professional support is particularly important in helping people to interpret aspects of their new situation as sick patients, for example, the significance of the diagnosis for their future well being.

Patients often have anxieties about their treatments. The need for professional support at this stage has been researched. Woods and Earp (1978) explored the concerns of women after mastectomy and showed that preparation for post operative experience was poor. Feeley *et al.* (1982) found that insufficient information about the disease and its treatment had been given to women with breast cancer. Anderson (1986) found that few of her respondents with breast cancer recalled receiving explicit information about what to expect emotionally or physically.

Hospital discharge can be both stressful and pleasurable for patients. They no longer have the cushioning hospital environment, supported by staff and fellow patients but have to face the longer term physical and psychological effects of their disease and its treatment and resume their usual domestic and other roles. Quint (1963) found that the impact of mastectomy struck patients most forcibly on their return home. Anderson (1986) found that most of her respondents with mastectomy felt that the advice and information given about the resumption of

activities of daily living on return home was scanty. Here was an area where women were looking for guidance and support from the nursing staff yet in relation to discharge planning, nurses in all the hospital studied were oriented to clinic appointments, not support in the community. Though most nurses could identify patients deemed to be 'at risk', there was no evidence to suggest that this awareness was translated into practice in liaison with community nursing staff and little evidence to indicate support from community nursing services other than for wound dressings. Community nurses identified a communication gap between hospital and community, a service gap in the provision of specific services like counselling and a time gap during which the patient could be unsupported for long spells between clinic appointments. Anderson (1986) pointed out the need for ongoing support for patients having mastectomy and that

Nursing care is not continuous with such an extended trajectory which is marked by boundaries as the patient passes from one stage to another. At these boundary points the patient is likely to be highly vulnerable to excessive stress. The nurse who seeks to enhance the existing abilities of an individual to cope with stress will recognise marker points in the career of the cancer patient like admission to and discharge from hospital, the commencement of treatment and points of recurrence of the cancer. p. 174

Recurrence of cancer is recognised in the literature as being even more stressful to patients than its diagnosis. There is little research indicating how patients can best be supported at this time. In the Macmillan Study, fear of recurrence was the commonest cause of patients' anxiety. Although patients with recurrence and advanced cancer formed only a minority of my sample, I hoped to learn what professional and informal support they perceived as alleviating their problems.

The cancer and social support literature says less about those times in illness when informal support is most appropriate. However, research has demonstrated the benefits of network members encouraging individuals to report abnormal symptoms to their doctors and the importance to patients' coping of experiential support from their peers.

4c What is the role for nurses in building up patients' informal support systems?

To what extent is knowledge of patients' informal support needs helpful to nurses? It is increasingly being realised that focusing care on patients without considering their network members, is an inadequate nursing approach. A 'systems approach' or

'family nursing' recognises that the behaviour of one family member affects the behaviour of another but not necessarily in a predictable or simple pattern. A family system is held together by the emotional investment of its members in one another. The central question for the professional carer is 'What is to be achieved for whom?' rather than 'Can this person benefit from the skills nurses have to offer?' It is important to realise that effecting change in one problem area will have differing impacts on others. For example, research has shown that breast cancer can cause stress for the patient's partner, sisters and children and this adversely affects the support they give to the patient. The helper is affected and changed by the family as is the family by the helper. Some nursing models use systems theory e.g. Roy (1976). However, the family as client has been embraced in principle but has never been fully operational. Whyte (1989) maintained that

... From the early stages of interaction with the family, a picture of the functioning family system can be drawn. The concept of wholeness is important, not just holistic care of the child who has the illness, but a holistic view of the family and the relationship of its parts. p. 308

She gave an example of the need for this holistic view of the family. When a spell of illness had the effect of causing a husband to give extra attention to the sick child and to sharing the burden of care with his wife, this dampened down stress levels to manageable proportions. Stress increased when a husband opted out, leaving his wife to cope unsupported. If the nurse was aware of patterns of informal support within the social network she could choose to compensate for the husband's deficit by providing support to the overburdened mother or she could help the husband to confront the reasons for his own behaviour and find a more positive response.

In a crisis such as illness, research demonstrates the importance for people's coping, adjustment and even survival of both formal and informal support. To give effective support, both formal and informal, people need greater understanding of how it operates-the aim of this thesis.

Chapter One

Literature Review

Social support has been defined variously. Qureshi (1990) defined it as

help or assistance or other evidence of caring provided through a person's social network,

Cobb (1976), as information leading individuals to believe that they are cared for, loved, esteemed and valued and belong to a network of communication and mutual obligation. Others have operationalised support as utilisation (spending time with people), availability (having someone there when needed), or satisfaction with support. O'Reilly (1988) noted that not all studies describing social support defined the construct. He found only modest agreement in conceptual definition out of 33 measurements. Frequently concepts were not or were ill defined. Six definitions were derived from Caplan (1974), Cobb (1976), Kahn (1979) and Weiss (1974). Looking for a conceptual link between of these authors, he identified three common elements;

- (1) an interactive process in which
- (2) particular actions or behaviours
- (3) can have a positive effect on an individual

There was no mention of why such attributes or behaviours had a positive effect.

In this thesis, I aimed to answer this question. I wanted to understand better which relationships and interactions patients with breast cancer found supportive and why and to compare and contrast their perceptions with definitions of support in the literature.

This literature review is divided into two parts;

- 1 Meanings assigned to social support through methods of its measurement
- 2 Sociological, psychological and nursing perspectives on the meaning of social support.

PART 1

Meanings assigned to social support through quantitative and qualitative approaches to its measurement

Kikuchi and Simmons (1992) claimed there are questions which only philosophy, not science, can answer, for example, 'What is the nature of the nurse-client relationship?' For these questions, they considered that the scientific mode of enquiry was inappropriate. Is it possible then to research the meaning of social support? Weber (1969) noted that sociology attempts an interpretive understanding of social action and argued that 'meaning' may be of two kinds.

The term may actually refer first to the actual existing meaning in the given concrete case of a particular actor, or to the average or approximate meaning attributable to a given plurality of actors, or secondly to the theoretically conceived 'pure type' of subjective meaning attributed to the hypothetical actor or actors in a given type of action. In no case does it refer to an objectively 'correct' meaning which is true in some metaphysical sense. It is this which distinguishes the empirical science of action such as sociology and history from the dogmatic disciplines in that area such as jurisprudence, logic, ethics, and aesthetics, which seek to ascertain the 'true' and 'valid' meanings associated with the objects of their investigation. p. 248

How valid is the 'meaning' of a concept when based on interpretation and intuition? Advocating a phenomenological approach to explanation and understanding in the study of health and illness, Benner (1985) argued that

meaning terms are essential when studying practical activity and relational issues, and that a privileged position is not gained by developing structural analyses or power terms that get behind and beyond meaning. p. 1

She maintained that the philosophical approach in which meaning can be seen in terms of representation of an independent reality is problematic when studying skilled performance and human concerns since all these activities and capacities are relational.

The differential attention paid to aspects of the situation varies with the situation in ways that cannot be quantified. Moreover, many of the aspects that are recognised cannot be reduced to mental representations One strategy for attending to meaningful distinctions in a situation is to reduce the distinctions to an array of patterns, with each pattern signifying a different meaning. p. 7

Many researchers have not defined social support explicitly. Its attributes have been inferred from the ways in which it has been operationalised. For example,

Gottlieb (1985) noted three meanings assigned to the social support construct, according to levels of social order at which it was operationalised in research

- 1 At the macro level, through social integration and participation in communities
2. At the mezzo level, through the properties of dyadic ties and personal social networks
- 3 At the micro level through a few close relationships/social intimacy.

He tentatively conceived of social support as

The feedback provided by contact with similar and valued peers. p. 9

1 Measuring social support as integration and participation; quantitative methodology

At the "Macro Level", researchers often spoke in terms of quantity of social ties. They measured peoples' involvement with institutions, voluntary organisations and informal community life, i.e. their social integration. Variables measured were quantity of relationships and frequency of contact. They were interested in the amount of support people received and how this related to their psychological and physical morbidity or coping with stress. On the basis of epidemiological research, Cassel (1976) hypothesised that disruption of social ties under stressful conditions increased susceptibility to illness and that group support could buffer individuals from harmful effects of stress. The positivist methodology used by these researchers incorporated natural science procedures. Haralambos (1985) noted that

The natural scientist is not required to explore and take account of the internal consciousness of matter in order to explain its behaviour. He can simply observe its behaviour from the outside. ...The results of those observations are regarded as objective facts, as data which are not distorted by the value judgements and ideology of the particular scientist. This is due to the availability of objective systems of classification and measurement. p. 494

Durkheim (1938) used this positivist approach to study suicide (1970), arguing that the fundamental rule of sociological method was to 'consider social facts as things.' He argued that the greater the integration of individuals within groups the less likely they were to commit suicide. However, integration cannot be calculated solely from the number of social ties. Although a large social network provides many social contacts, this may not ensure that support is accessible or perceived as helpful. Some social ties result not from choice but from circumstances. While people choose

their spouses, they do not choose their parents-in-law and although contact with them may be frequent, it may not be perceived as supportive. Parsons (1949) acknowledged the constraining character of social facts while recognising subjective processes of interpretation through which they were reproduced. He argued that people were socialised into societies through internalisation of their norms. His theory omitted the inner conflicts which might intervene and interrupt this process.

1a Positivist research techniques

Positivist research techniques use standardised protocols which aim to generate data influenced neither by research setting nor researcher (Selltitz *et al.* 1964). In experimental studies, comparison of two or more groups controls for the effects of extraneous variables. However, some social support research can lack external validity if laboratory designs are used. Kessler (1983) questioned whether experimentally induced stressors such as noise or mild electric shocks could be considered comparable to natural stressors such as bereavement or unemployment.

2 Measuring social support as social intimacy and attachment; a phenomenological approach

At the "micro level" of the social order, Gottlieb (1985) noted that social support was measured by the quality and content of peoples' intimate relationships. This approach reflects the belief that social support stems from the quality of social ties such as attachment, intimacy, and empathy. The phenomenological theory behind such an approach is that people do not merely respond to an external society but create their own meanings, construct their own reality and direct their own actions. Haralambos (1985) noted that phenomenologists criticised the positivist approach used, for example, by Durkheim (1970) because;

To treat social reality as anything other than a construction of meanings is to distort it. ...For example, to see official statistics on crime and suicide as referring to activities which have an objective reality of their own is to misunderstand their nature. Such statistics are simply the meanings given by social actors to the events which they have perceived and interpreted as crime and suicide. p. 498

2a Phenomenological research techniques

Phenomenological research techniques include participant observation, and unstructured interviews. Denzin (1970); noted that phenomenologists prefer open ended to structured interviews because;

1. They allow respondents to use their unique ways of defining the world.
2. They assume that no fixed sequence of questions is suitable to all respondents.
3. They allow respondents to raise important issues not in the schedule. p. 125

However, Hammersley and Atkinson (1983) argued that if the interviewer asked very few questions, respondents might be faced with problems of what was relevant.

Gottlieb (1978) used a phenomenological approach to explore meanings of social support for single-parent mothers. Responses were collapsed into four kinds of support, emotionally sustaining, problem solving, environmental and indirect personal influence. A phenomenological approach implies that meanings individuals give to situations are paramount. This makes generalising of research findings to other situations difficult. Clegg and Dunkerly (1980) voiced this criticism in relation to interactionist research.

First it reduces the wider society simply to a meaningful environment of 'stocks of knowledge' for the environment is no longer a deterministic constraint under which people labour. Second, although it has a great deal to say about organisational processes, it cannot say very much about organisational structures, except by reducing them to face to face processes. Third, in denying the direct impact of external structures like technology, it tends to become purely subjectivist. p. 277

Denzin (1970) maintained that it was possible to generalise from descriptions to theories. For example, Becker's (1953) study of Marihuana users generated a theory about stages in 'moral careers' from novice to 'old hand'. Important in this was his study of process as well as stability, examining how symbols and behaviour varied over time and setting. Hammersley and Atkinson (1983) did not recommend either the avoidance or uncritical acceptance of respondents' accounts but that researchers work with available knowledge, recognising that it might be erroneous and subjecting it to systematic enquiry.

3 Measuring social support as social integration and social intimacy; a synthesis

Some social support research employed insights and methods of both positivism and phenomenology, using standardised questionnaires to elicit factual data and unstructured interviews to record respondents' perceptions. Studying the effects of social relationships on survival in women with breast cancer, Waxler-Morrison *et al.* (1991) obtained data by questionnaire on size of social network, interviewing some respondents about types of support obtained and reasons for loss of relationships after the cancer diagnosis.

Silverman (1985) advocated research which synthesised positivist and phenomenological approaches, concerning itself with the influence of social structures on individual action and processes of individual interpretation through which structures were reproduced and sometimes changed e.g. the 'realist' approach. Bhaskar (1979) stated this position;

Society does not exist independently of human activity (the error of reification) but it is not the product of it (the error of voluntarism). p. 45

Silverman (1985) saw elements of the realist approach in the work of Michel Foucault (1977). Foucault maintained that power did not work in a centralised, uniform way but in 'multiple forms of subjugation' which extended beyond formal rules and became embodied in particular techniques. The exercise of power could be subject to multiple points of resistance by individuals. He criticised both the functionalist approach to research and that of the interactionists who could never explain the unintended consequences of action. Strauss (1987) argued that in qualitative research the emphasis on interaction was often so strong that it had prevented attention to the larger structural conditions. For Silverman (1985), interview data display cultural realities which are neither biased nor accurate but simply 'real'.

Interview data from this point of view are not one side of the picture to be balanced by observation of what respondents actually do or to be compared with what their role partners say. Instead, realism implies that such data reproduce and rearticulate cultural particulars grounded in given patterns of social organisation. p. 157

Silverman maintained that when analysing interview accounts, researchers have to use commonsense knowledge but this is insufficient to provide validity. Data

should be rigorously scrutinised, e.g. in group data analysis sessions. He also advocated quantifying data where appropriate.

At the mezzo level, some researchers operationalised social support by examining properties of personal social networks. Social network analysis takes account of both structural factors, and individuals' interpretations of the meaning of interactions. Pearlin (1985) noted that just as wealth, power and status are unequally distributed in society so are the scopes of networks and what they offer to members. Networks have various functions, one of which is support. Study of networks therefore provided information about contexts in which social support was given or withheld. It allowed exploration of support available through dyadic ties and the network as a whole and could combine insights into the 'macro' and 'micro' approaches. Through total network analysis, themes like the norms of membership could be explored. Size of network could be related to levels of support received. House and Kahn (1985) maintained that studies should measure three aspects of social relationships (a) existence and quantity (b) aspects of network structure (c) functional content and quality. Gottlieb (1985) advocated network analysis in exploring support resources available to individuals through the structural properties of their social orbits and the quality and content of support provided by their closest relationships. Wellman (1983) maintained that network analysis was part of a paradigm shift from categorical to relational, structural analysis. By treating the content of ties as flows of resources, it transformed the study of support into the study of supportive resources and linked the allocation of these resources to large scale social phenomena.

However, he criticised much social support research for looking only for supportive ties, failing to recognise the variegated patterns of relationships forming most networks. He claimed that by treating support as a variable that may or may not occur, the circumstances under which a tie did or did not provide support could be analysed.

PART 2

Sociological, psychological and nursing perspectives on the meaning of social support

To explore the meaning of social support, I analysed sociological, psychological and nursing literature in deductive and inductive ways, in keeping with grounded theory as defined by Glaser and Strauss (1967);

The analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them in order to develop his theory as it emerges.

I took this statement to refer to the literature as well as the data and treated the literature as another data source which both raised questions and provided answers to help develop my theories. This literature review is divided into six parts;

- 1 The meaning of social support
- 2 Effects of illness on individuals' identities
- 3 Effects of social support on health and adjustment to illness
- 4 Social support for identity in illness
- 5 The role of formal support in illness
- 6 The roles of formal and informal support in identity maintenance in illness

1 The meaning of social support

Do quantity and/or quality of social relationships influence perceptions of support? If so, why do they have this effect?

1a Purpose and meaning through social integration

Is there any evidence that the size of an individual's social network is an indicator of support and if so, why?

The functionalist sociologist, Durkheim (1970) maintained that the greater people's social isolation, the more life lacked purpose and meaning. Lack of social integration produced 'anomie', a lack of shared norms and values. The latter seemed to be an important part of a person's identity. Social isolation increased the risk of

suicide. Although not referring to social support, Durkheim argued that the more family ties bound a person to the domestic group, the less likely he was to commit suicide. In cases of religious affiliation, Durkheim used similar arguments. Protestant communities had higher suicide rates than catholic counterparts. Durkheim argued that the catholic religion integrated its members more strongly by uniform belief and standardised ritual. Durkheim's theory seems to indicate that social support comes from shared values. Although research has shown that psychological health is related to the number and availability of supportive ties, there is difficulty in demonstrating a causal link. Functionalists have emphasised that norms and values attached to social roles provide guidelines for behaviour. The implication is that social roles and statuses support the identities of the individuals concerned and that people are socialised into the culture of their society. However, it seems likely that the amount of social support people receive doesn't depend solely on their social roles or number of social ties. Personality and social competence are likely to affect their capacity for building and maintaining social support.

Support from peers is one way by which individuals who have become unsure of or lost their status are reintegrated into society or into the norms of a 'deviant' group. In an American study of peer counselling, Swaffield (1981) noted that most groups provided a world within a world where the 'deviant' was given a voice and accepted as part of a collective. Peers can serve as role models for each other, learning new ways of resolving shared dilemmas. A study by Vachon *et al.* (1980) showed both individual and group peer support facilitated the adaptation of recent widows to their new status, allowing them to achieve greater emotional and social integration. Peer groups provide opportunities to give as well as receive. When members contribute to other's well-being this enhances a sense of self worth and reduces feelings of powerlessness. Self help groups can help a sick or disabled person because people in crisis often need to share and compare their own reactions with others similarly affected. This may ameliorate the sense of isolation often reported by patients with cancer. In a research review, Van den Borne *et al.* (1986) found no studies indicating a negative effect of fellow patient contact on patients' ability to cope with cancer. Falke and Taylor's (1983) survey of support groups suggested that patients with cancer turned to support groups because family interactions were stressed and family members did not understand the problematic nature of the cancer experience. For those who experienced withdrawal of family and friends, a group replaced social support. Sometimes, learning how to talk to

family and friends about their cancer reversed the process of mutual withdrawal that otherwise occurred. Peer groups sometimes give rise to stress as well as support. Dunkel Schetter (1984) noted three conditions in which interaction with peers might be damaging;

- 1 If it results in self deprecating social comparisons.
- 2 If other group members model behaviours which reflect loss of control over feelings.
- 3 If there is an encounter with a member who has relapsed

Falke and Taylor (1983) noted that women were more likely than men to join support groups. They may also be more susceptible to support group interventions.

1b Security through intimacy/attachment

Attachment is one indication of close relationship. How does attachment provide support? One way seems to be through security. The psychologist, Bowlby (1971) examined processes of attachment and separation, noting how young children responded to temporary or permanent loss of a mother figure by becoming very distressed. Bowlby's research incorporated data on how animals responded to a mother's presence or absence. Harlow and Zimmerman (1959) had shown that infant monkeys spent more time with a cloth mother surrogate than a wire surrogate which provided milk. The cloth monkey provided security while the infant monkey explored its cage while holding onto "mother" with one hand. A sense of security seemed to be more important than food. Bowlby (1971) maintained that for most people, the bond with parents continues in adult life with attachment often developing towards people outside the family and towards groups and institutions.

Other researchers have supported this. Eighty per cent of women in O'Connor and Brown's (1984) study named at least one person to whom they felt close apart from their husbands and children, the average being 1.8. They noted that the majority of North American studies typically recorded a much larger number of friendships. Bowlby (1971) also claimed that temporary attachment figures could provide a secure base from which an individual could explore self and his/her relationships. This has obvious implications for professionals trying to provide support. Weiss (1974), an American sociologist studying the effects of bereavement, separation and divorce, suggested that the relationship providing attachment is probably primary, around which others are organised. He noted that for adults, marriage is the most

common provider of attachment, although other cross sex and same sex relationships can provide it.

In crisis, support is particularly likely to be sought from attachment figures (Bowlby, 1971). Fears diminish in their presence but increase in their absence. In crisis, adults often become more demanding of others and an increase in attachment behaviour is evident. Close relationships can aid adjustment to cancer but sometimes they make it harder (Lichtman and Taylor 1986). In a two year follow-up of patients' psychological and social adjustment to mastectomy, Morris (1979) concluded that about 75% of patients with breast cancer adjusted emotionally and socially to the experience. Their close relationships with family and friends continued to be supportive. For the others, close relationships were not as smooth. Similar results have been reported for patients with gynaecological cancers.

1bi Stability/permanence through intimacy/attachment

Boyce (1985) postulated an elemental human need for stability. He maintained that the work of Erikson (1965) supported this claim. In his formulation of critical periods in psychological development, Erikson spoke of basic trust as the first crucial accomplishment of the human infant.

The infant's first social achievement, then, is his willingness to let the mother out of sight without undue anxiety or rage, because she has become an inner certainty as well as an outer predictability. Such consistency, continuity and sameness of experience provide a rudimentary sense of ego identity. p. 239-40

The mother's support provided the stability needed for development of the infant's identity. Boyce (1985) suggested that a sense of permanence is a representation of the meaning of social support in children's lives and social support is a frame of reference from which personal experience is organised and upheld.

Mother-infant interactions, family routines, affiliations with friends and observances of cultural traditions - each becomes regarded as a particular manifestation of social support, all bound together by their common capacity to suggest and sustain a single meaning, a sense of what is permanent and enduring. p. 168

I maintain that this sense of permanence is also an important factor enabling adults to meaningfully organise their lives.

Psychoanalysts have stressed the need for intimacy, often implying that from it come all other forms of social growth and constructive interaction. Erikson (1965) postulated the capacity for intimacy as another major developmental life task, ideally achieved in a close relationship with a person of the opposite sex. Lowenthal and Haven (1968) supported this view but claimed there are other forms of intimacy.

Intimate relationships seem to act as a buffer against social losses. From the research of Bowlby (1971) and Weiss (1974), close relationships can provide emotional support, love and security. There is much evidence that loss of a close relationship through separation or divorce (Bloom *et al.* 1978) or through death (Parkes 1972, Raphael 1977) is associated with psychological and physical morbidity. Loss of an attachment figure cannot easily be replaced by support from other relationships. Researching within an organisation called "Parents without Partners", Weiss (1974) discovered that friendly interaction with others in the same plight was inadequate to compensate the separated or divorced for their loss. Friendships provided reassurance that separation or divorce was not any individual's fault but happened to others. Weiss (1975) distinguished between the loneliness of *social isolation* which could be mitigated by friendships and the loneliness of *emotional isolation* which was untouched. I see this as a distinction between the kind of support provided by social integration and that provided by social intimacy. Social integration gave reassurance that individuals were not isolated in their distress but their situation was shared by others. Social intimacy provided support for many aspects of the individual's identity not just those under threat at any particular moment. Weiss (1975) defined emotional loneliness as that which could only be remedied by involvement in a mutually committed relationship. Bowlby (1981) also noted that different types of affectional bonding cannot be regarded as identical. Loneliness following the death of a spouse is not usually assuaged by the presence of a child. Different relationships support different aspects of a person's identity.

Loss of roles and social contacts sometimes accompanies old age. Intimacy may protect people from the effects of such losses. Lowenthal and Haven (1968) found that an intimate relationship served as a buffer against the stress involved in role loss or reduced social interaction. They explored the effects of intimate

relationships on health by interviewing a sample of 280 elderly people. Their analysis rested mainly on responses to "Is there anyone in particular you confide in and talk to about yourself or your problems?" This was followed by a description of the confidant. The presence of a confidant was positively associated with indicators of adjustment while absence was related to low morale. An intimate relationship served as a buffer against social losses in role and interaction and against more traumatic losses accompanying widowhood and retirement. Qureshi and Walker (1989) also found that the degree of contact between elderly people and their families correlated significantly with measures of morale, but not with the degree of felt loneliness. The existence of a close relationship with someone in the family was significant in relation to loneliness. Qureshi and Walker (1989) maintained this indicated that quantity of contact may not be of significance compared with quality in overcoming loneliness.

1biii Self worth through intimacy/confiding

The ability to reveal deeper aspects of 'self' to another and to feel accepted seems to be very supportive. Several studies have shown that access to a confiding relationship is important to health. There is evidence that people who have a confidant, report more positive mood status than those without (Bunch 1972, Miller and Ingham 1976). The ability to confide in someone may provide support by increasing feelings of self worth. Brown and Harris (1978) research showed the presence of a confiding relationship, particularly with a husband/boyfriend was associated with reduced risks of depression, once a major loss or disappointment occurred. They suggested the feelings of self worth linking with such support were particularly important in reducing risk. In a study of depression in mothers of young children, Brown and Harris (1986) stressed the importance of the quality of the marital relationship for the married and of confiding relationships for single parents. Other studies have obtained comparable results using the same measures of life events and confiding relationships. (Brown and Prudo 1981, Costello 1982, Murphy 1982). Porrit (1979) found little relationship between availability of social support and outcome in crisis, but the quality of social support (e.g. empathic understanding, respect and constructive genuineness) was related to outcome. This echoes Carl Roger's (1957) theories that therapeutic relationships provide respect, genuineness and unconditional positive regard. In a study of close relationships of married women, O'Connor and Brown (1984) found that the number of close/confiding relationships reported was related to mental health and positive

self evaluation. However, they argued that there is no guarantee that those to whom an individual *feels* most attached will be those providing support. A close relationship was characterised by a high level of interaction and intimate confiding. They found 70% of women with a close relationship were without an affective disorder, compared with 43% of other women. The number of persons the women named as very close was also related to positive self evaluation. Intimate confiding was unrelated to ongoing dependency but *felt* attachment was highly related to it.

1c Development, maintenance and transformation of identities through relationships in social networks

One insight developed from the study of social networks was the role of social support in the development, maintenance, and transformation of social identities. Functionalist sociologists implied that social integration supported the individual's identity and that human behaviour and attitudes were shaped by norms of society. Interactionist sociologists, in contrast, did not see human behaviour as a response to the system. In their view,

Meanings are created, developed modified and changed within the actual process of interaction. Haralambos (1985, p. 16)

Interactionists suggested that the individual develops a self concept from interaction because the self is largely a reflection of others' reactions. Apart from instrumental support, various investigators give credence to the theory that social support is interactions which develop, maintain and transform social identities. House (1981) distinguished the various elements as emotional support, appraisal support (affirmation, feedback) informational support and instrumental support. Bloom (1982) added a fifth component, social affiliation. In a study by Hoppe *et al.* (1982) of survivors of Hodgkin's disease, several measures of support were included. Emotional support was strongly related to informational support and network size but not to tangible support. It can be inferred that emotional support, informational support and network size all provided feedback which supported social identity.

1ci Development of identities through supportive relationships

There is considerable research on how identity develops, is maintained or changed. Mead (1934) argued that the individual develops a self concept through role taking. In the first stage of this process, children play roles other than their own. and

become aware of differences between themselves and the roles they play. In the second stage, children come to see themselves from others' perspectives as participants in the game, or the 'generalised other.' Mead's theories have been developed by other sociologists who recognised that individuals incorporated only the norms of those groups in society which had become significant to them but of which they might not yet be members. Sherif (1953) called these groups 'reference groups' to contrast them with membership groups. The former influenced attitudes and behaviour and moulded identity. Raimy (1948) who first defined the self concept noted that it results from present and past self observation and is the map which each person consults in order to understand himself, especially during moments of crisis or choice. Combs and Snygg (1959) maintained that those perceptions about self which seem most important to the individual are the self concept-

the very essence of 'me' whose loss is regarded as personal destruction. p. 127

The individual arrives at some perceptions through his explorations of self. Most he acquires from interactions with people about him.

Human personality is primarily a product of social interaction. We learn the most significant and fundamental facts about ourselves from ... reflected appraisals, inferences about ourselves made as a consequence of the ways we perceive others behaving towards us. p. 134

In addition to his most personal self, the individual differentiates significant others such as mother, father, sister, friends. These are experienced as real parts of the self so that when they are lost through separation or death the individual often has the feeling that a part of himself has also been lost.

1cii Maintenance of identities through supportive relationships

Combs and Snygg (1959) reduced many human needs to one basic need, the striving for adequacy, and claimed in their interactions with others, people sought to maintain and enhance their identities. Families provide children's earliest experiences of adequacy or inadequacy.

If each act is seen as an attempt to fortify the individual's perception of personal adequacy, behaviour becomes meaningful. p. 45-46

The search for adequacy also involves a search for self consistency. The phenomenal self with the self concept as the core, represents the individual's

fundamental frame of reference, and is highly stable and resistant to change. In a crisis, when a redefinition of self may become necessary, much encouragement may be needed to make possible this shift.

Hirsch (1981) maintained that self redefinitions can be facilitated by social networks which are personal communities supporting social identities. Various life spheres such as family, friends, occupation and leisure have their own sets of identities. Some overlap and can change over time. Networks of small size, strong ties, high density and homogeneity and low dispersion seem to be helpful in maintaining social identity and well being. The viability of social identities depends greatly on their recognition in the social network. Individuals' personal communities also reflect their values and choices. The process of maintaining social identities is thus interactive between people and their significant others.

1ciii Changes in identities through supportive relationships

Change in social roles and identities seems to be facilitated by larger networks with weaker ties, lower density and greater social heterogeneity. Attempts to build new social identities to cope with new tasks may require individuals to make changes to their networks. Hirsch (1980) studied the social networks of two groups of women, facing life transitions. One comprised recent young widows and the other women returning to full time university studies after long absence. Women with low density networks, with greater separation of family and non-family roles were more able than those with high density networks to successfully make transitions involving increased interactions outside the family sphere and decreased emphasis on domestic identity. Women with multidimensional friendships involving sharing with the friend at least two activities important to the respondent, made more successful transitions than those with unidimensional friendships based too much around family or children. Erikson (1965) suggested that satisfactory identities need to be established within each of the major life spheres. According to Hirsch (1981), social networks should support social identities over time and provide opportunities for further development. However, he noted that limited opportunities may restrict alternatives from which a new social identity and social network can be created. Alternatively, individuals may lack personal and social competence to build up supportive personal communities. Tolsdorf (1976) demonstrated failure by schizophrenic patients to build up and use supportive personal networks. Although they were in a dependent role, medical patients extended the same amount of

support as they received. Schizophrenic patients received more support than they gave. Their networks tended to be dominated by kin, frequently reported to be hostile. Schizophrenics held negative network orientations and viewed it as inadvisable, useless or potentially dangerous to draw on network support. Most of the medical patients solicited and followed advice more frequently than did schizophrenics. Psychiatric patients tended to cope with stress through self help, whereas medical patients, after trying to help themselves, sought support from their network members, resulting in resolution of stress and control of their situation.

The most obvious ways in which networks support individuals' identities is through verbal acknowledgement. Networks can also provide identity support through more subtle, implicit means, for example, socializing with family and friends, interacting with work colleagues.

1d Development of negative self identities through unsupportive relationships

Network analysis takes account of negative and positive sides of social relationships. Gottlieb (1985) maintained the social orbits in which people are embedded are not always capable of supporting victims of crises. Wellman (1981) found that only a minority of close ties of Toronto residents were supportive, 30% providing support in emergencies and 22 per cent in dealing with everyday matters. Some relationships were neutral, some harmful and some mixed. Wellman (1981) noted that non supportive ties may be important in other ways, for example, in the time spent on them or in the indirect access they give to potentially supportive relationships. Revenson *et al.* (1991) considered social network interactions as a potential source of both stress (problematic support) and support (positive support) for individuals with chronic illness. They interviewed patients, recently diagnosed with rheumatoid arthritis. Analysis examined conjoint effects of social support and problematic interactions on symptoms of depression. Respondents reported receiving moderate to high levels of positive support from their close social networks. All respondents reported some degree of problematic support from at least one network member. Receipt of positive support from close relationships was related to lower depression, Receipt of problematic support was related to increased depression. A positive-problematic support interaction suggested that costs of problematic support did not cancel out the benefits of positive support. Patients who reported little support and a greater degree of problematic interactions experienced the highest level of symptoms.

Network members or professionals may feel unable to support a person when their own identities are threatened by some aspect of the individual's circumstances. In a study of nurses' communications with patients with cancer, Wilkinson (1991) analysed audio-taped histories completed by registered nurses for patients newly diagnosed with cancer, patients with recurrence, and patients receiving palliative care. Findings indicated an overall poor level of facilitative communication, with a patient's recurrence causing most difficulties. There was evidence that the way nurses communicated depended on the environment created by the ward sister, the nurses' religious beliefs and attitude to death, rather than specific education in communication. Wilkinson noted that

It appears that nurses who have high anxiety regarding their own death protect themselves from being reminded of death and dying by using blocking verbal behaviours so that, as a result, they are not subjected to the patient's emotions and distress. p. 687

1di Development of negative identities through labelling and stigmatising

Social interactions can undermine people's identities if they negatively label or stigmatise them. Labelling shows how a person's identity is not rigidly fixed but is influenced by others' behaviour and attitudes. Labelled people are grouped into 'types' of person and certain kinds of behaviour are expected of them. Goffman (1968) wrote of the stigma attaching to those who occupy devalued roles, its effects on their self concepts, and the efforts of stigmatised individuals to retain self esteem and present a reputable public image. In a study of patients' experiences in self management of diabetes mellitus, Nyhlin (1990) found that diabetics worked hard at creating an appearance of normality.

It is humiliating to have to reveal one's diabetes and to pronounce oneself as sick. The diabetic person would rather prefer to be shown consideration primarily as the person he is instead of having to show that he is diabetic. p. 64

Peer groups can support identities of stigmatised people but they still must face the different expectations and definitions of 'normal' society. Shumaker and Brownell (1984) noted that the self identity function of support refers to learning who we are, and that social interactions can have negative effects on social identities.

Scapegoating, labelling, stereotyping and stigmatising are all examples of how we can obtain a negative sense of self through our interactions with others. p. 23

Giaquinta (1977) noted that those close to cancer patients sometimes place the blame for cancer, often seen as unclean and sinful in origin, on patients. Wortman

and Conway (1985) noted that cancer can evoke aversion if others are afraid of catching it or if they see previously healthy individuals become changed by the disease or treatment. Encounters with those who are ill can make people feel threatened. Attributing the illness to another's undesirable personal characteristics or behaviour provides a sense of protection. Interacting with a seriously ill person may result in feelings of awkwardness, inadequacy or frustration because there seems little to say or do. There is evidence that against the backdrop of these negative feelings, people believe they should remain optimistic and cheerful in their patient interactions, resulting in behaviour that is unintentionally damaging to the latter. Such behaviour may include avoidance of the patient and of open discussion about the illness. Wortman and Conway claimed that the ill person might interpret these behaviours as rejection just when others' support was important. Wortman and Dunkel-Schetter (1979) claimed that victims of cancer elicited negative feelings in others resulting in behaviour that patients often interpreted as rejection. This claim was given credibility in Peters-Golden's (1982) study of breast cancer patients, where approximately 75% of respondents agreed that people treated them differently after learning they had cancer. Of these, 72% reported that they were misunderstood, over 50% indicated that they were avoided or feared, 14% felt pitied and only 3% felt that people were nicer to them than before. Patients in Peters-Golden's (1982) study also reported that others oversolicitous attitudes made them feel incompetent to perform ordinary tasks. Support for Wortman and Dunkel-Schetter's (1979) hypothesis that victims of cancer elicit negative behaviour in others comes from studies inspired by Lerner and Miller's (1978) 'just world hypothesis' which claimed that people tend to devalue those who suffer innocently thus allowing observers to retain belief that the world is a just place and that people generally get what they deserve. However, other research has found that patients with cancer do not elicit totally negative responses. In a later study, Dunkel-Schetter (1984) herself found that of 79 patients with cancer, 95% indicated that they were receiving as much understanding from their spouse or significant other as they needed. Neither Peters-Golden's (1982) nor Dunkel-Schetter's (1984) research used a control group to assess effects of cancer on emotional support. Dunkel-Schetter (1984) did find that about 25% of respondents experienced significant interpersonal problems with family, friends and work colleagues. Eighteen per cent reported negative reactions in at least one family member, mostly lack of support. Zenmore and Shepel (1989) tested the just world hypothesis by administering social and emotional adjustment inventories to women who had

undergone mastectomy for breast cancer and women with benign breast lumps acting as controls. They found that perceived emotional support correlated with adjustment but contrary to Wortman and Dunkel-Schetter's (1979) analysis, patients with cancer perceived greater emotional support from friends and family than did controls. Women who reported being able to talk about their concerns with at least one friend or relative scored higher on social and emotional adjustment and on self esteem than women unable to confide in others. These relations held for patients with cancer and for controls. Zenmore and Shepel's (1989) findings together with those of Dunkel-Schetter (1984) conflict with reports that patients with cancer feel unsupported, and with the literature which suggests that people blame and avoid victims. Past research has however, concentrated on strangers' reactions to innocent victims. The findings of Zenmore and Shepel (1989) suggested that family and friends may behave more positively. However, they reported no negative attitudes or behaviour experienced by their respondents and it is difficult to believe that there were none.

Methodological standards in this research area have not been uniformly high. Assessment of social support and adjustment have often not been rigorous. Generalisation of findings is in doubt since most studies have been conducted with patients with breast cancer. Despite limitations, some consistent findings have emerged. The literature suggests that the majority of female patients with cancer continue to be sustained by most of their close relationships as they adjust. However, some patients with cancer are victimised by their families and friends. (Bard and Sutherland 1955, Dunkel Schetter 1984). Isolated incidents of rejection are relatively common and strains in otherwise satisfying relationships may also develop. These strains typically involve communication problems. In my opinion, an alternative to the 'just world hypothesis' is that some people respond negatively to cancer victims because their own identities are threatened by aspects of the disease. Reviewing the literature on the impact of chronic disease on families, Litman (1974) concluded that some families show deterioration in solidarity, others improve and the majority show no change. Factors that appeared to determine the degree of impact were the severity of the illness, its chronicity, and pre-existing family solidarity.

1e Conditions for the provision of social support

Two factors seem to be involved in provision of informal support, reciprocity and normative beliefs about caring. The first describes an interactive process between helper and helped, the second a more passive role for the recipient of support.

1ei Reciprocity as a condition for provision of social support

Gouldner (1960) maintained that people usually return benefits received from others. Greenberg (1980) argued that accepting a benefit may place the recipient in a state of indebtedness and the latter will want to reduce this discomfort by not accepting the benefit or reciprocating it. Shumaker and Brownell (1984) defined social support as

an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well being of the recipient. p. 13

This definition does not mention benefits of the exchange to the provider. However, Shumaker and Brownell acknowledged that mutual caring cannot be reduced to a cost/benefit analysis. Abrams (1978) described informal care as produced and sustained by a balance of reciprocity, affect and trust. Independent attainment of social rewards such as affection, warmth or respect is impossible and requires interaction with others. According to Blau (1964), one function of mutual assistance over time is the establishment of bonds of affection which make exchanges more rewarding when carried out by some individuals than others. Blau sees the existence of such intrinsic rewards from particular relationships, as one feature of social exchange which distinguishes it from purely economic exchange.

Chesler and Barbarin's (1984) research with parents and friends of children with cancer, showed that support was given within a context of mutual concern rather than in expectation of repayment. However, friendships were also concerned with protecting each others' identities threatened by aspects of the crisis. This process of protection may diminish support being given or received. Parents were concerned about sharing information about the illness, because it might have increased their own emotional distress by resurfacing their initial shock and pain. They were also concerned that their friends would be worried by the child's diagnosis. Friends were shocked by the illness and were reluctant to raise painful topics with parents in case they increased their distress.

There are no social networks which are totally supportive. Individuals in relationships both offer support to and require attention from others. Thus, there is a balance of support and strain in identity support. However, some networks are predominantly supportive while others are mixed or stressful. Even when network members intend to offer support, they may increase the recipient's stress. There is evidence that the closest relationships can be stressful at times. In illness, an individual's network members may feel their own identities are so threatened by the illness that they are unable to give support. Peters-Golden (1982) found that only half of her respondents with breast cancer felt adequately supported. She suggested that support may not be forthcoming when potential helpers feel threatened by the patient's situation, sensing their own vulnerability. Waxler-Morrison *et al.* (1991) examined the relationship between women's social contexts at diagnosis and their survival from breast cancer four years later. Respondents reported complex patterns of support and protection between family members which were often experienced by the women as ambivalent and sometimes very stressful. Women felt young adult children were least supportive and reported having to support them by being cheerful and carrying on as if things were normal, since children of this age appeared fearful for their mothers' lives. Some children stayed away during the most stressful periods.

Often people who were at one time receiving support, can offer it to others. Spiegel (1981) observed such transitions commonly in self help groups. They were essential to their effectiveness. Waxler-Morrison *et al.* (1991) found many breast cancer survivors were active care-givers. Wortman and Dunkel-Schetter (1979) maintained that because patients with cancer suffer great uncertainties, they have increased support needs. However, there are barriers to receiving this support. Some are self imposed to protect those close to them, others arise because loved ones sometimes have feelings of fear and aversion to cancer.

1eii Normative beliefs about caring as a condition for provision of social support

Studying carers of older people, Qureshi and Walker (1989), found that neither reciprocity nor affect were necessary conditions for the provision of support. Normative beliefs were important in influencing who did the caring.

The rules are that close relatives are preferred to more distant ones, any relative is preferred to a non relative, and female relatives are preferred to male relatives. p. 123

Carers were chosen in accordance with this hierarchy in 62% of cases. Other factors influencing who did the caring were household type (joint or not), proximity of potential carers, health of household members. Taking these into account, decisions about the correct helper/helpers conformed to the model in 75% of cases. Three reasons for failure to discharge obligations emerged; other normative obligations, relative's incapacity, elderly person breaking rules of acceptable behaviour. Where help was given, people usually felt a sense of obligation to their parents for past help but a significant minority did not share these feelings, feeling compelled to help by pressures external to the relationship. However, reciprocity was one of the main foundations of the caring relationship. Qureshi and Walker (1989) found a relationship between help given by relatives to the elderly person currently and the reported help previously given by the elderly person. The majority of carers considered that there was currently nothing that the elderly person did for them, although just over half of all children and over one third of all other carers reported receiving regular past help. There was a clear association between the perception that the relationship had always been one sided and a lack of emotional closeness.

2 Effects of illness on social identities

Illness can affect individual's identities in many ways. Cohen and Lazarus (1979) noted six possible threats;

1. to life itself
2. to self concept and future plans
3. to emotional equilibrium
4. to bodily integrity and comfort
5. to accomplishment of customary roles and social activities.
6. those associated with adjusting to a new physical and social environment

They have listed the threat of illness to the self concept separately from five other threats. However, research findings lead me to support Combs and Snygg's (1959) assertion that all perceptions of the self which are vital to the individual, comprise the self concept. Self concept includes perceptions of having a future, bodily integrity, social roles, status. The relative importance of each aspect to the individual determines the degree of threat perceived. I discuss the threats posed by illness to identity as follows.

- a to life, future plans
- b to physical and psychosocial independence
- c to body image and sexuality
- d to social roles/status
- e to relationships

2a The threat of illness to life and future plans

An important aspect of identity is a sense of stability, permanence and security. Serious illness can cause uncertainty and anomie and may threaten life. Cancer has a negative public image being a feared disease because of its associations. The Cancer Relief Macmillan Fund (1988) conducted a U.K. study into public attitudes to and knowledge of cancer. It was noted that

It is cancer which is seen to be society's main health concern, and it is cancer that people are most worried about getting personally. ... Improved levels of knowledge contrast sharply with attitudes towards cancer, which are still unduly negative and fearful. Over 40% of the sample agreed with the statement that 'the fear of cancer is worse than the fear of death.' p. 5

Attitudes became more positive and knowledge more accurate when cancer was broken down into different types. Negative attitudes towards cancer were demonstrated in a longitudinal study by Leventhal *et al.* (1986) of women with breast cancer, (some in adjuvant treatment and others in treatment for metastatic disease) and patients with lymphatic cancer. Most patients in both groups viewed their cancer as recurrent or chronic and doubted its curability. However, 79% of patients in metastatic and adjuvant groups saw positive effects of the disease for the 'self', including an increased willingness to live the way they wanted. Patients in both groups were less likely to see positive outcomes for their families, 42% of the breast cancer sample reported positive consequences for the family, (e.g. increased closeness), while 31% cited negative consequences, (e.g. less involvement, interference with plans). In the Cancer Relief Macmillan Fund (1988) study, respondents were asked 'What does the word cancer mean to you?' The main responses were as follows;

Death/killer disease/fatal/incurable	34%
A tumour/growth/malignant growth	23%
A frightening word/frightens you	16%
Disease of body/deterioration of the system	15%
There are various forms of cancer, some are malignant, some are benign	13%

Long term suffering/painful illness and painful treatment	9%
Gradually eats away/wastes away the body	9%
Spreads/progresses unless caught early	9% p. 17

This very negative image applies to health professionals too. In a research review, Corner (1988) noted that attitudes to cancer of the public and health care professionals were largely negative and stereotyped. She noted studies by Bond (1978), McIntosh (1977) and Quint (1965) which reported avoidance behaviour by nurses and doctors in their communications with patients with cancer. Solodky *et al.* (1986) studied nurses' responses to case histories of patients with heart disease and cancer. All responded in a negative and stereotyped way concerning prognosis for patients with cancer who were perceived to be less likely to be cured, with a shorter life expectancy, being less in control of their illness and less likely to receive effective treatment. This negative stereotype was unaffected by their experiences of cancer or by their level of education. Ray (1982) noted that public surveys had presented a negative view of cancer

Cancer is an umbrella term. However, in the public's mind these distinctions are masked and there is a general stereotype which emerges from surveys that is associated with pain and death and that is looked on with some dread. p. 3

It is not surprising that patients share with the public a dread of cancer. Meyerowitz (1980) observed three problems during rehabilitation of patients with breast cancer;

1. depression, anxiety and anger.
2. disruption of everyday life patterns, including marital and/or sexual relationships.
3. Fear of danger and mutilation of cancer and mastectomy.

In a study of effects of cancer on patients' lives, Mages and Mendelsohn (1979) maintained that since people with cancer were confronted with stress over an extended time, it was inaccurate to speak of cancer as a single event, requiring an immediate adaption. Cancer treatment often entails irreparable physical damage which may enforce changes in activities and self perceptions. In such circumstances, return to an original equilibrium is precluded. Most patients with cancer reported permanent changes in self perceptions and their future existence due to confrontation with mortality and the continuing unpredictability of their future. Mages and Mendelsohn conceptualised 'psychosocial transitions' as a more

appropriate description of evolving effects of cancer. They found positive and negative changes balanced out for women, preserving their self esteem. Among men, the perceived decline in activity, assertiveness and striving for achievement, created a less positive self image. Even after treatment for cancer, people cannot be sure of non-recurrence. Writing about her breast cancer experience, Lorde (1980), a black American, noted;

I was also afraid that I was not really in control, that it might already be too late to halt the spread of the cancer. I think perhaps I was afraid to continue being myself. p. 33

Many researchers have noted that the main threat of serious illness is to life itself. Lynam (1990) noted that young adults with cancer in her research saw cancer as forcing them to confront their mortality. Anderson (1988) found that after mastectomy for breast cancer, women felt continuous uncertainty about potentially disastrous and poorly predictable future events.

Uncertainty and fear of recurrence were ever present. The women coped by 'keeping happy', by 'counting their blessings' and by 'making the most of today'. p. 43

Hilton (1988) found that areas of uncertainty for 16 women with breast cancer included being unable to foretell the future, feeling insecure, being in doubt and not being able to rely on someone or something. Negative emotions were associated with uncertainty and positive emotions with surety. In a qualitative study of patients with breast cancer, Gyllenskold (1982) found that all patients talked to her about death. The disease and its treatment meant women were confronted with their own mortality. Ray (1982) noted that the discovery of cancer means the individuals have to come to terms with the possibility of dying, not just in some distant future, but;

Within the almost here and now, the psychological present, and in circumstances that can all too readily be imagined. p. 3

Shands (1966) described this as an information crisis. Ray (1982) noted the key feature of this information crisis was ambivalence about how patients viewed themselves. They were neither ill, nor healthy, but in an 'at risk' role. Consequently, they found themselves repeatedly testing for symptoms of recurrence, not knowing what significance to attach to general aches and pains. Lorde (1980), described the threat of breast cancer to her previous identity as a well woman.

I do not forget my cancer for very long ever. I live with the constant fear of recurrence of another cancer. Sometimes fear stalks me like another malignancy sapping energy and power and attention from my work. A cold becomes sinister, a cough, lung cancer, a bruise, leukaemia. p. 289

One aspect of identity already mentioned was a sense of permanence of the self. This can be threatened by serious illness. Lorde (1980) described her own experience.

The acceptance of death as a fact rather than the desire to die can empower my energies with a forcefulness and vigour not always possible when one eye is out unconsciously for eternity. p. 26

She felt her temporary status on earth had been emphasised.

Every once in a while I would think 'What do I eat? How do I act to announce or preserve my new status as temporary upon this earth? And then I'd remember that we have always been temporary and that I had just never really underlined it or acted out of it so completely before. p. 52

Moch (1990), conducted a descriptive study of women's experiences with breast cancer. She concluded that illness provides opportunities for self knowledge. Women reported changed relatedness, identifying meaning within the experience, adding new perspectives about life and often described themselves as very different from how they were before the illness.

2b The threat of illness to physical and psychosocial independence

Illness can make people feel they no longer control their bodies, especially if causes are uncertain and preventive measures unknown. Many types of cancer fall into this category. In the Cancer Relief Macmillan Fund (1988) study, it was noted that the public's awareness of causes of cancer was quite high. However, there was also high appreciation of its indiscriminate nature. The main reasons for thinking one might get cancer were;

It can happen to anyone	37%
I smoke/am in contact with smokers	15%
Father/mother died of it/it's hereditary	9%
It's in the system and something starts it off	4%
Radiation increasing in the environment	4%

p. 23

Adults accustomed to independent living may experience any kind of dependency as humiliation. Abrams (1978) reported that some older men clung to independence more than older women did, leading them to reject relatives' help. Qureshi and

Walker (1989) found that carers of the elderly found the balance between help and respect for independence difficult to strike. In 1983, Burish and Lyles noted that cancer treatments rarely gave control and responsibility to patients. In some instances, notably breast cancer, patients are now becoming more involved in treatment decisions. Lorde (1980) described her feelings after making a breast cancer treatment decision.

I think now what was important was not what I chose to do as much as that I was conscious of being able to choose and having chosen was empowered from having made a decision. p. 33

2c The threat to body image/sexuality

Sexuality influences how individuals view themselves which in turn affects their ability to relate to others. There is social pressure on women to conform to public images of feminine attractiveness. Writing about obesity, McCrea (1984) said

Probably never before has dissatisfaction with the female body (especially) been so widespread because we are bombarded with hints as to how we should look and inevitably most fall short.

Breasts are important to female sexuality. Tait (1988) noted that notions of body image can be partly seen as a social construction. The threat of breast surgery is dependent not merely on the cultural values of the patient's society but also on the significance that the breast holds for each individual. For a minority of women the threat of losing a breast because of cancer is more significant than having a life threatening disease. Some women feel strongly society's pressures on them to conform to a stereotype of feminine attractiveness, even after cancer. However, Lorde (1980) saw breast cancer less as a threat to her physical self and more to herself as a writer and to her relationships.

I would have paid more than even my beloved breast out of my body to preserve that self that was not merely physically defined and count it well spent. p. 32

After mastectomy, she felt that the emphasis by health care professionals on the cosmetic, reinforced society's stereotype of women and refused to wear a breast prosthesis noting;

With quick cosmetic reassurance, we are told that feelings are not important, our appearance is all, the sum total of self. p. 57

There has been much research into the effects of mastectomy on women's body image and sexuality. Studies by Morris *et al.* (1977) and Maguire *et al.* (1978)

compared psychiatric morbidity in women treated for breast cancer by mastectomy. with that of women with benign disease. They showed that in the year after mastectomy, 25%-33% of women experienced depression, anxiety or sexual dysfunction. Gyllenskold (1982) found that most women did not consider what their breasts meant to them until faced with their loss.

When a woman is faced with breast loss, she may regard this as a threat to her feminine identity or an injury to her own personality and integrity. p. 238

Gyllenskold found that those women who grieved briefly for their breast loss were incapable of working through the crisis to a new orientation. Burish and Lyles (1983) noted that following mastectomy, many women, especially those for whom appearance had been of great importance (Bard and Sutherland 1955) felt worthless, ugly, defeminised, socially and sexually unacceptable. Maguire *et al.* (1978) found that up to 25% of patients who had had mastectomy experienced psychosexual and body image problems. It was not the surgical extent that was the key but that any treatment was necessary. Anderson (1988) noted that the immediate response of women with mastectomy was to liken the wound to a disfigurement. Four weeks later, most women were 'learning to live with it.' Finding or adapting clothes was a matter of concern as was being lopsided and coping with the temporary prosthesis which fell out of place readily. Eighty per cent of the women found the permanent prosthesis satisfactory and 64% found it comfortable.

As clinical trials showed no difference in breast cancer survival rates between women treated by mastectomy and those treated by local tumour excision, surgeons offered breast conservation for small tumours. Researchers then compared the psychosocial outcomes of mastectomy and breast conservation. However, Fallowfield (1991) noted a consistent finding in such studies that levels of anxiety and depression were the same regardless of the treatment given. Fallowfield felt this might be because not all the studies asked about fears of recurrence. In a prospective study involving women with early breast cancer, Fallowfield *et al.* (1990) reported that the majority gave the fear of cancer as their worst thought rather than breast loss, irrespective of the surgical treatment received. Only 12% of women felt that losing a breast was a worse fear than having cancer. Denton and Baum (1983) found that women whose prime concern prior to surgery was breast loss rather than having cancer were more likely to require psychiatric referral later. Few studies included questions on sexual functioning, but in a study of the psychological outcomes of lumpectomy and mastectomy, Steinberg *et al.* (1985)

found no difference on a measure of sexuality, between treatment groups pre-operatively but after surgery, almost all the severe sexual dysfunction in both patients and their spouses was in the mastectomy group. This study used measures to separate the woman's own responses from those they perceived in their husbands. Fallowfield *et al.* (1990) pointed out that women who failed to adapt to breast loss were nine times more likely to develop sexual difficulties. She recommended that all women be offered reconstruction irrespective of age and marital status. Studies have shown that immediate breast reconstruction reduces psychological morbidity significantly (Dean *et al.* 1983, Schain *et al.* 1983).

The knowledge that one has cancer also produces changes in identity. Blackmore (1988) noted that psychological changes are general to all cancer types.

The knowledge for example, that there are cellular changes within the body outside the control of growth and differentiation leads to anxiety and depression and a sense of self loss. p. 138

Mages and Mendelsohn (1979) found a decline in sexual interest and activity was normal in patients being treated for cancer.

Non surgical cancer treatments also threaten sexual identity. Krumm (1982) noted that patients receiving radiotherapy feared being burned, becoming radioactive, disfigured, or sterile. These fears had great impact on body image. Chemotherapy induced alopecia continues to be a distressing side effect, depending on the degree of importance placed by patients on hair. Baxley *et al.* (1984) showed that patients with alopecia had a poorer body image than those without hair loss.

Fears of being rejected or found undesirable can cause patients to withdraw from sexual activity. Breast cancer patients have received extensive psychological study. Andersen (1986) noted that estimates of general sexual disruption, lowered frequency of intercourse or specific difficulties range from 21% to 39% of patients sampled retrospectively. Anderson (1988) reported that when asked about effects of mastectomy on sexual activity, 73% of Scottish women she studied said there was no change. Of the 16% acknowledging a changed interest, various explanations were given e.g., 'I'm conscious of the lack of a breast'. Burish and Lyles (1983) noted that impaired sexual functioning was sometimes indicative of one of the most frequently reported consequences of mastectomy, disturbed marital relationships. Two prospective studies have been conducted. Morris *et al.* (1977) interviewed 69 patients with breast cancer and 91 with benign disease. At the three month follow

up, sexual satisfaction for cancer patients had significantly deteriorated. However, at the two year follow up approximately 30% of patients in each group reported dissatisfaction. Maguire *et al.* (1978) also studied patients with breast cancer, treated by mastectomy and patients with benign breast disease. Four months after treatment, the incidence of sexual problems did not differ between groups. However, the intensity of problems differed, with 40% of the patients in the breast cancer sample having moderate/severe difficulties against 12% in their benign sample. Andersen and Hacker (1983A) found that women without sexual partners at the time of initial cancer treatment who consequently underwent change to their bodies and/or their ability to engage in sexual activity, were at risk of more difficult adjustment and not resuming sexual activity. In a study of women treated with mastectomy, Metzger, Rogers and Bauman (1983) reported that sexual dysfunction was particularly problematic for younger divorced or separated women, rather than married, widowed or spinsters in the same age group. Women's concerns with disfigurement needed to be interpreted both in the context of body image and as a concern affecting their relationships with men.

2d The threat to social roles and status

Identity is bound up with social roles. In a study of the impact of breast cancer on patients and husbands, Northouse and Swain (1987) found that the greatest concern of many hospital patients was whether they would return to previous lifestyles. Women with small children said family concerns were their primary worry. Both spouses experienced strain during hospitalisation. Husbands had difficulties juggling work responsibilities while visiting and supporting their wives. Patients reported more vocational, domestic, and social problems. Vocational difficulties centred on taking time off work, domestic difficulties resulting from limited arm movement interfering with housework, social difficulties resulting from tiredness.

One way in which people can lose their social status is through stigma. Goffman (1968) defined stigma as

The situation of an individual who is disqualified from full social acceptance; a person who has a failing or a handicap is reduced in the mind of society as a tainted person. The word stigma originated from the Greeks to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. p. 11

Cancer remains a stigmatising disease because of its often unknown causes and its associations with suffering and death. Sontag (1979) saw similarities in previous public perceptions of TB and present perceptions of cancer.

The fantasies inspired by TB in the last century, by cancer now, are responses to a disease thought to be intractable and capricious, that is a disease not understood in an era in which medicine's central premise is that all diseases can be cured. Any disease that is treated as a mystery and acutely enough feared will be felt to be morally if not literally contagious. Thus a surprisingly large number of people with cancer find themselves being shunned by relatives and friends and are objects of practices of decontamination by members of their household, as if cancer, like TB, were an infectious disease. p. 1-2

Sometimes stigma is visible. sometimes not. Alopecia following chemotherapy, is noticeable to everyone. A mastectomy can be concealed. Goffman (1968) suggested that

When a person's differentness is not immediately apparent, he then has to decide whether to tell or not to tell, to let on or not to, to lie or not. p. 57

A woman with breast cancer may be conscious of her stigma whether or not it is obvious to others. With breast cancer, Lorde (1980) felt an outsider.

... it was hard not to feel like a pariah. There were people who avoided me out of their own pain and fear and others who seemed to expect me to become someone other than who I have always been, myself, rather than a saint or Buddha. ... The status of untouchable is very unreal and a lonely one, although it does keep everyone at arms length and protects as it insulates. But you can die of that specialness, of the cold, the isolation. pp. 48-49

Donavon and Pierce (1976) identified three components of adaptation to disability; a change in values so that physical characteristics become less important, not allowing disability to affect uninvolved body areas or unrelated behaviours, viewing the physical factor or altered function as an asset.

Combs and Snygg (1959) identified the basic human need as a striving to maintain and enhance identities. Illness can lower self esteem. In a qualitative study, Johnson (1991) noted that heart attacks undermined self confidence and self worth in many respondents.

Throughout these changes, the heart attack victim must struggle to preserve a sense of self. He or she must struggle to maintain a personal identity other than one of patient or invalid. ...The informants indicated that much of their sense of self worth was related to what they did as mothers fathers, workers, spouses, men and women. The heart attack disrupted these well defined roles. p. 40

Many women said they preferred to give rather than receive care and they attempted to protect their mothering roles. Being patients prevented the male respondents from continuing their breadwinner role and without this they felt 'useless.' Burish and Lyles (1983) noted that following mastectomy, most patients experience depression, anxiety and reduced self esteem.

2e The threat to relationships

Combs and Snygg (1959) reported that effective relationships are close to the core of 'self.' Changes to a sick person's self concept resulting from the illness may affect the way in which others relate to him/her and vice versa. Changes in network members' attitudes and behaviour may be supportive or unsupportive. Relationships may be lost as a consequence of network members' own identities being threatened by the illness. In her study of young adults with cancer, Lynam (1990), found that cancer was perceived as threatening relationships which were seen as part of self. However, research has indicated that illness adversely affects only a minority of relationships of sick people. Moch (1990) mentioned changed relatedness as an experience of patients with breast cancer. Increased richness in relatedness was experienced as others' expressions of caring, feeling closeness to others and sensing a receptivity to others e.g. a need to comfort. On the negative side, women experienced increasing distance/disconnectedness in some relationships and fear from others, and a realisation of loneliness. Revenson *et al.* (1991) worked professionally with patients with breast cancer and described their complex patterns of ambivalent, sometimes negative relationships with spouses and families. To protect her family, the woman with breast cancer may not reveal her anxieties to them. Consequently, her spouse and kin may not offer appropriate support. Waxler-Morrison *et al.* (1991) also noted that relationships like marriage sometimes provided ambivalent support to patients with breast cancer because of past events, future expectations and obligations over which women had relatively less choice or control. They reported people sometimes receiving more effective support from outsiders such as friends than from family. Friendships were usually less encumbered with past and future obligations than family ties and women perceived the help of friends to be generally unambivalent. However, some women lost friends, either temporarily or permanently, who couldn't tolerate life threatening illness. Neuling and Winefield (1988) observed that friends provided less support of every kind than families did, yet satisfaction with support given by friends was

greater than that from family members. This was perhaps because people expected more from family than from friends.

Krause (1987) found that marital relationships of women with breast cancer were either not influenced by the illness or were improved by it, only 2 patients reporting negative effects. Most patients had discussed their illness with their family and friends. In a study of families in which the mother had breast cancer, diabetes or fibrocystic disease, Lewis *et al.* (1989) found that breast cancer did not have a significant negative effect on the marital relationship, although diabetes and fibrocystic disease did. Spouses of wives with breast cancer explained away their wives' behaviour in terms of the illness, whereas spouses of women with diabetes or fibrocystic disease did not. Hough *et al.* (1991) conducted a smaller study as part of Lewis *et al.*'s (1989) research, interviewing 11 families with extreme scores in marital satisfaction and depression. Five families were 'well adjusted' and six 'poorly adjusted.' Well adjusted families constructed positive meaning from the illness experience, perceived themselves as competent and spoke positively about support from family and friends. Poorly adjusted families were subject to more stressors, regarded the illness negatively, and perceived a lack of support from family and friends. Both the larger and smaller studies supported the notion that an emotionally satisfying and secure spousal relationship was paramount to the family's successful adaption to the mother's chronic illness. These results were also consistent with Peters-Golden's (1982) finding that husbands' inability to offer support resulted in most distress to women with breast cancer. Why is the marital relationship so crucial to healthy adjustment to chronic illness? Weiss (1974) suggested that for adults, marriage is the commonest provider of attachment and probably the primary one. Northouse and Swain (1989) found that both patients with breast cancer and husbands reported distress significantly above the level reported for the normal population, their greatest concern centring around survival. Seventy two per cent of women reported a positive reaction from their husbands to their incisions, 13% a worried/hesitant reaction, and 4% a negative comment or refusal to look. Eleven per cent were unsure of their husbands' reactions. Seventy six per cent of husbands reported no difficulty in seeing their wives' incisions, 12% reported mild difficulty and 12% great difficulty. The latter spoke of disfigurement and thought the incision spoiled their wives' appearance. Typically, those husbands who did not discuss the incision with their wives, appeared to attach more sexual importance to breast loss and did not see the incision until their wives returned home. Husbands and family were primary sources of support, but when in hospital,

women also identified nurses and doctors. Husband's sources of support tended to be family, friends and work associates. Husbands seldom regarded health professionals as sources of support. Lichtman (1982) found that the quality of the marital relationship was unchanged or increased after mastectomy. When strains occurred, it was often because husband and wife had different views on the best way to cope with the disease. An established marriage may have a buffering effect on initial reactions to mastectomy.

3 The Effects of Social Support on Health and Adjustment to Illness

Social support has been found to correlate with health and its absence with physical and psychological morbidity. The epidemiologist John Cassel, hypothesised that disruption of social ties increased susceptibility to illness and that group support could buffer individuals from the harmful effects of stress.

Network size and frequency of social contact have been positively associated with physical and psychological health. House and Kahn (1985) noted that

... simple measures of existence and quantity of social relationships are relatively objective, reliable There is also substantial evidence for their construct validity in terms of their relationships with health outcomes. p. 90

Berkman and Syme (1979) examined mortality rates of a sample of Californians in relation to their social contacts nine years earlier. People with the lowest initial social contact levels had mortality rates that were two to four and a half times greater than those with many social contacts. This index still predicted mortality when statistical controls were introduced for respondents' initial state of health, socio-economic level, involvement in health risk behaviours and use of preventive health care services. Those with many social ties seemed more protected from illness and death than those with few but the study did not reveal what aspects of social ties provided protection. Shoenbach *et al.* (1986) also reported that individuals with higher social integration scores were at lower risk of mortality than more isolated people, after controlling for risk factors such as cigarette smoking and serum cholesterol levels. Reviewing social support literature, Callaghan and Morrissey (1993) noted that social support is thought to affect health by;

- 1 regulating thoughts, feelings and behaviour to promote health (House *et al.* 1988).
- 2 fostering a sense of meaning in life (Antonovsky 1974).
- 3 facilitating health promoting behaviour e.g., diet, exercise, appropriate use of alcohol (Umberson 1987).

They noted that few studies have provided evidence of more than tenuous links between the variables representing health and those representing social support.

Is quality more important than quantity of relationships in promoting health and protecting from disease? Gottlieb (1985) noted research reporting quality as a stronger predictor of health outcomes than quantity. Lowenthal and Haven (1968) found that an intimate relationship was more closely associated with mental health than was high social interaction or role status. People with confidants could decrease the number of their social roles with no effect on morale. For those without confidants who retrenched in their social lives, the odds for depression became overwhelming. This finding echoes Weiss' (1974) observations that social isolation in divorced or separated people could be mitigated by new friendships, but emotional isolation remained untouched. A combination of social and emotional isolation could be devastating.

3a Social Support and Psychological Health

Studies have evaluated the impact of social support on psychological morbidity. Brown *et al.*'s (1986) study of working class women in London reported lack of support from a partner or confidant correlated with increased risk of depression. Working class women at home with young children, with little support from friends or partners, had higher rates of depressive illness than middle class women with more support. However, low income and poor housing may also cause depression. In an Australian study, Henderson *et al.* (1978) reported a strong inverse relationship between social bonds and the presence of neurotic symptoms, especially for close ties. However, in a later study, Henderson (1981) found the risk of neurosis was increased by the *perception* of inadequate social bonds, rather than by their absence. Bloom (1982) found that social support directly affected women's coping with breast cancer and indirectly affected their adjustment. One indicator of adjustment was self concept, others being psychological distress and sense of power. Coping was assessed on positive and negative items. Four measures of support were used;

The woman's perception of family cohesiveness.

Perception of social contact

Perception of amount of leisure activity.

One indicator of social identity feedback, having a confidant.

Bloom found that perception of family cohesiveness and the amount of social contact had direct effects on coping and indirect effects on all three adjustment measures. Having a confidant did not have this effect. Bloom reported that women who had more supports had a higher self concept, felt more powerful in their illness experience and underwent less psychological distress. Marital status was not found to be an important predictor of adjustment. This supported Bloom's contention that perception of support, rather than existence of social ties is critical.

Literature has indicated that social support defined as emotional support is related to decreased distress during crisis. Bloom and Spiegel (1984) analysed data from women with metastatic breast cancer. It was predicted that the greater the perception of emotional support, the greater the sense of psychological well being and the greater the individual's opportunities for social exchange, the better the perception of social functioning. Emotional support by one's family was significantly related to outlook on life. Family support was not related to social functioning, whereas social activity was.

3b Social Support and Physical Health

Physical morbidity and mortality have been found to be influenced by social support. Social support in illness has been found to be associated with survival. Blazer (1982) found that perceived adequacy of social support in an elderly community correlated with decreased risk of mortality. Ramirez *et al.* (1989) found that severely threatening life events were significantly associated with recurrence of breast cancer. The study was limited by its retrospective nature and the need for exploration of the interaction between severe life stressors, coping behaviour and social support. Nevertheless, there are indications here of support needed for women with breast cancer, not only at diagnosis but during follow-up. Waxler-Morrison *et al.* (1991), found that survival was significantly affected by number of supportive friends/persons, whether a woman worked, was unmarried, extent of contact with friends and social network size. The extent to which a woman felt she could call on three or more friends for support was most associated with survival.

3c Social support and adjustment to effects of illness and treatment

Adjustment has been defined in several ways. Some authors have measured psychological well being (Brown *et al.* 1975, Holahan and Moos 1981) while others have monitored social functioning (Bloom and Spiegel 1984) or physical well being (Berkman and Syme 1979, Finlayson 1976). Vachon (1984) compared effects of support on adjustment in women with breast cancer and those recently widowed. Both groups were assessed soon after the life event and 2 years later. Lack of support during the initial crisis was predictive of high distress 2 years after both events.

4 Social support for identity in illness

Several writers pointed to differences between the health sustaining (everyday) and stress reducing (crisis) functions of support. Among the health sustaining effects of support, Schumaker and Brownell (1984) included affiliative needs, self identity maintenance and self esteem enhancement. Among its stress reducing functions, they noted problem solving behaviours, cognitive appraisal and cognitive adaption. Gottlieb (1985) categorised support as involving emotionally sustaining as well as problem solving behaviours. His list of 26 informal helping behaviours was derived from a study of low income, single mothers, (Gottlieb 1978), based on participants' identification of helpful behaviours. Emotionally sustaining behaviours were those that enabled people to feel cared for and esteemed.

4a Support in reducing the stressor

Whatever seems inconsistent with existing self perceptions may be experienced as threatening. Lazarus (1969) and Lazarus and Folkman (1984) argued that people assess the significance of stressors for their well being. At the stage of primary appraisal, support can broaden their perceptions of events, and increase understanding by providing information about stressors, and by efforts to soften or remove them.

4b Coping support

Unfortunately, people often become defensive and their behaviour less adaptable under threat. Psychoanalytic theories claim that support restores peoples' coping abilities, helps them to clarify problems and to make decisions. Brown and Pedder

(1979) described three levels and aims of the psychotherapy. Level one is 'support,' its therapeutic component being ventilation of feelings and discussion of problems to facilitate decision making. No contract is established between helper and client, only recognition of the other's need for acceptance. The helper would provide support while building up the person's own coping capacities. Egan (1990) presented a three stage problem management model of helping. The stages are;

- 1 Identifying and clarifying problems and unused opportunities
- 2 Developing a preferred scenario
- 3 Formulating strategies and plans.

In serious illness, professional helpers need to be involved in all of these stages. Gerald Caplan (1976) characterised social support as helping people cope with stressful situations by;

Mobilising their psychological resources to deal with emotional problems;

Sharing their tasks;

Providing them with money, materials, skills, information, and advice. p. 21

Lazarus and Folkman (1984) defined the coping process itself as secondary appraisal. Support could broaden coping options through modelling of emotional and behavioural coping strategies, by referring people to professional services and by providing information and problem solving techniques. Using Lazarus' work as a framework, Kelly (1991) emphasised sociological aspects of coping after surgery (ileostomy). He maintained that public identities are constructed as people interact with others and that during the process, meaning develops. Kelly identified four levels of coping. The technical level was skill based and concerned how people coped with stoma care. The intra-subjective level was the locus of the 'self-experience' and place where the 'various mechanisms of the presentation of self or psychological defence' operated. The inter-personal level was that aspect of coping where people interacted with others, some of whom shared knowledge of the ileostomy, others who didn't. In these interactions, the self was either sustained or rejected in the identities constructed. The inter-subjective level was concerned with how people accounted for and justified their past, present and future actions. The 'self' interpreted and reinterpreted what had happened. Mages and Mendelsohn (1979) identified three categories of coping in patients with cancer.

- 1 Techniques to minimise distress, e.g. avoiding disturbing thoughts and feelings.
- 2 Attempts to deal with stress, e.g. seeking information, involvement in treatment decisions.
- 3 Turning to others for support.

Peters-Golden (1982) noted that turning to others facilitated better emotional adjustment, greater coping skills and higher self esteem. Practical help can be important in helping people to cope with illness. This may include family members temporarily taking over some of the sick person's roles and professionals giving skilled help.

4c Support in maintaining/making changes in identity

When aspects of people's identities are not supported within their networks, new relationships may need to be developed. Waxler-Morrison *et al.* (1991) reported that some women with breast cancer found new friends who had had breast cancer and who helped. Sometimes new friendships were established with fellow hospital patients. Contact with peers signals reduced isolation and enabled women to compare notes about effective coping strategies. In a personal introduction to his overview of social support research, Gottlieb (1985) described how his sister built a new social network to support her new identity after multiple sclerosis was diagnosed.

Gradually, as the disease took its toll on her mobility, and she became redefined by her peers and her spouse as a disabled person, both her casual and her intimate social ties became loosened, eventuating in the termination of her marriage and her job. ... It was not until she moved to Los Angeles and began attending an outstanding MS clinic that she was gradually able to put herself and her life together again. ... She was able to weave a new network composed of other victims and their relatives, and she began to establish a new identity that was not predicated solely on her status as an MS patient. p. 6

4ci Enhancing self esteem

Caplan (1976) maintained that families can help people accomplish 'worry or grief work' during a crisis, enabling them to adapt to their situation. Those suffering from a bereavement or serious illness often feel a loss of personal worth which families can counteract by validating their value. When a person is ill or disfigured, such support is important to self esteem (Caplan 1974, Moos and Tsu 1977, DiMatteo and Hays 1981). Working with women with breast cancer, Taylor (1983)



hypothesised that people undergo three processes to cope cognitively with threatening events;

- 1 a search for the meaning of events.
- 2 an attempt to gain mastery over their lives
- 3 the enhancement of self esteem.

She maintained that a strong counterbalance to self esteem threats is having a confidant who makes a person feel accepted and valued. Lynam (1990) conducted a qualitative study of young adults with cancer and found that;

Supportive interactions were those which assisted patients to respond to threats to identity that were associated with the diagnosis of cancer. p. 169

Her respondents all saw cancer as a potential threat to 'who they were,' defining themselves in terms of their social roles and relationships and their associated feelings. Supportive interactions were those that assisted individuals to redefine themselves and to see themselves as managing.

4cii Reducing uncertainty

Johnson (1991) found that to gauge their progress, heart attack victims set goals, reviewed their progress and made comparisons with others worse off than themselves. Reassurance was primarily sought from health care professionals and from other heart attack victims.

Confidence in coping can be increased or diminished by reference groups' reactions. In a study of women's adjustment to breast cancer, Bloom (1982) noted that;

When facing a new situation, the knowledge that the feelings being experienced are not unique but are a common experience of those facing similar contingencies reduces the sense of isolation and temporary disorganisation of self resulting from the uncertainty of the diagnosis, treatment sequence. A second aspect of social identity support is the provision of feedback by others on the appropriateness of current behaviour patterns. p. 1331

4ciii Support for autonomy

People in crisis need to reduce uncertainty and regain control of their lives. Controlling bodily functions, emotions, social roles and making plans are important to identity. Johnson (1991) found that many heart attack victims felt vulnerable and afraid of having another attack. To regain a sense of control, they sought

reassurance, learned about the heart and practised cautiousness. Wilson *et al.* (1988) conducted a study to determine whether, if given choice, patients with breast cancer would prefer mastectomy or conservation treatment. Only two regretted their choice. They concluded that these patients were capable of choosing treatment and should do so. In a study of women with early breast cancer, Fallowfield *et al.* (1990) found that women offered treatment choice, seemed to have less psychiatric morbidity than others who did not. Fear of cancer and recurrence were compelling factors in determining treatment preference. They maintained that many women wanted more adequate information as to why one treatment was recommended over another, rather than the ultimate decision as to surgical therapy.

4civ Sexual identity support

Sexual relationships were a source of anxiety for Kelly's (1991) respondents with stomas, especially the unmarried and unpartnered. He noted that;

The prospective sexual encounter is especially threatening because it contains within it the possibility of rejection, which in sociological terms means that the identity as normal or ordinary, which the person may work so hard to project, is not legitimated. p. 121

A partner's support for a patient's sexual identity threatened by illness is likely to be very important to adjustment. Waxler-Morrison *et al.* (1991) found most married breast cancer survivors they interviewed reported supportive spouses. However, the threat to life was occasionally enough to break up a marriage when the woman's husband could not tolerate a wife with cancer. Longitudinal data indicate that if women are to develop sexual difficulties, the majority will be evidenced in the early months of recovery (Andersen *et al.* 1986, Maguire *et al.* 1978, Morris *et al.* 1977). Andersen (1986) noted that it would help to include the sexual partner in any supportive intervention. It was important that patients were informed of the potential effects of cancer treatments on sexuality and general health. Depression and anxiety could be problematic for upwards of 40% of all cancer patients.

5 The role of formal support in illness

Formal support is artificial in the sense that it is introduced into a situation. It is provided by paid workers whose role is to provide specific forms of help. Froland *et al.* (1983) defined formal support as services which;

operate under a system of explicit categories for assessing need or eligibility, formal rules of procedure, specialization and formal co-ordination among helping roles, definitions associated with client or consumer status, consistency of standards for treating problems, independent of personal characteristics and objectively stated criteria for what constitutes progress. p. 265

The sociologist, Max Weber (1946) maintained that work in a bureaucracy is governed by rules not personal considerations such as feelings towards clients. Control is exercised through bureaucrats' specialist knowledge. By contrast, informal support is provided by kin, friends and neighbours. Froland *et al.* (1983) maintained that informal care is;

highly pluralistic and differentiated in the types of people involved, what they do and why. Help is provided as part of a continuing set of mutual exchanges that constitute a larger system of rights and obligations within a primary group, neighbourhood or culture. p. 264

Informal support is usually grounded in longstanding relationships, free from the financial and social stigmas sometimes associated with formal support. Informal support depends on experiential rather than expert knowledge and follows local norms about when and how to express support.

The term social support is often taken to mean informal support but a few authors have described statutory workers as part of an individual's social support network, under certain circumstances (for example, Hooyman 1983). Dunkel-Schetter (1984) noted that patients with cancer mentioned health care providers as frequently as family members as sources of greatest help. One hundred and fifty two 'most helpful' sources were identified, of whom 34% were family, 30% medical or nursing staff and 16% friends. Qureshi and Walker (1989) noted divisions between formal and informal sectors could be overcome by thinking of 'social support networks' rather than informal support networks. Social support networks could be created to meet specific needs and comprise both formal and informal helpers. Allan (1983) referred to this purposive integration of informal carer and professional as a care partnership.

Ill people often need professional support but the best way to use it has not always been clear. Maguire *et al.* (1980) evaluated the contribution of a specialist nurse in reducing post mastectomy psychiatric morbidity. After 12 to 18 months, anxiety, depression and sexual problems were all less common in the counselled group than in controls. Although counselling failed to prevent morbidity, the nurse recognised 76% of those needing psychiatric help. Only 15% of the control group needing such

help were recognised and referred. Content of counselling was not described but the authors suggested that it might be more effective if commenced at diagnosis, enabling the nurse-counsellor to establish an early supportive relationship.

Is support increased by frequency of contact or is it just as effective if delivered when needed? Lugton (1987) found that access to hospice home care nurses was more important to patients and relatives than frequent visiting. Availability encouraged relatives to feel that expert help was always at hand from someone trusted. This gave relatives confidence in caring for the dying person at home. Building up a relationship with one nurse also ensured consistency of dialogue. Problems could be followed through properly. Wilkinson *et al.* (1988) studied the effects of limited counselling of patients with breast cancer by specialist nurses, and the effects of counselling by ward and community nurses who had undertaken a brief counselling course. In the limited intervention group, the specialist nurse limited her visits and placed the onus on patients to contact her about problems. Monitoring/counselling did not prevent the occurrence of psychological problems. However, the limited intervention group experienced fewer psychiatric problems (13%) than patients in either the unlimited intervention group or the ward and community group (24%), although few results were statistically significant. Patients in the limited intervention group did less well in physical or social recovery.

In a study by Watson *et al.* (1988), forty patients with breast cancer were randomised to receive either routine care or counselling by a nurse at diagnosis, prior to hospital admission, before surgery, prior to discharge, at home, at follow-up and in event of recurrence. Emotional support gave patients opportunities to express feelings, discuss problems and feel in control. Information reduced misconceptions about cancer and uncertainties about treatment. The study indicated more rapid adjustment for counselled patients. Bloom (1979) found that information and emotional support for mastectomy patients decreased feelings that health was outside their control. Dunkel-Schetter (1984) found that information and advice were reported as helpful to patients with cancer when provided by health professionals; attempts by non-experts seemed to be disliked. In a study of support in a neonatal intensive care unit, McHaffie (1992) found that parents drew information mainly from professionals and disliked grandparents advising or informing them. References were made to their lacking medical understanding, being out of date, or merely wishing to reassure the parents. The principal role of grandparents was to provide emotional support for parents.

5a Effects of power in formal relationships on identity maintenance

Sick people need support enabling them to regain control, and enhance self esteem. Professionals do not always empower their clients. In a study of cancer patients' interactions with health professionals, Payne (1991) noted that medical interviews were dominated by professional agendas and it took several visits before doctors and patients discovered appropriate ways of interacting. Shanley (1984) noted three types of psychiatric nurse-patient relationship; custodial, medical and social. In the social model, therapeutic relationships depended on tolerance for relatively unstructured situations and relinquishing of formal role relationships, control and authority. Thomson, Melia and Boyd (1983) described the relationships which can develop between dying people and professional carers as 'covenant' relationships. Carers are at the limit of what they can do curatively and offer palliative care, support and befriending. They encourage dying people to be involved in treatment decisions.

5b Superiority of informal over formal support?

Abrams (1977,1978) maintained that informal care is superior to formal care, because it is embedded in pre-existing social relationships and can make people feel cared for rather than serviced. The special quality of informal care rests on perceptions that the provision of practical services is only part of a relationship between giver and recipient. However, bureaucracies have greater resources and professional expertise than most families. Qureshi and Walker (1989) maintained that superiority of family care cannot be accepted unquestioningly because of its unequal gender division in caring and destructive relationships that occurred in some families. Also, recipients of state provided services could see these as evidence of caring about them. Formal carers could provide the intrinsic rewards of affection and interest. The impersonal nature of formal support may be seen as advantageous by some recipients since formal carers are detached from past family quarrels and have no future expectation of return for services rendered.

5c Identity maintenance; Common elements in formal and informal support

Are there common elements in formal and informal support which are important for identity maintenance? Froland *et al.* (1983) found that formal and informal support could be complementary if stock were taken of appropriate roles and responsibilities of professionals and informal caregivers.

In a study of social support and recovery after breast surgery, Neuling and Winefield (1988), found that while different patterns emerged in support needs from professional and informal sources, empathetic support was required from all sources;

Patients require empathetic and informational support from health professionals ... yet by far the most frequent complaints of too little empathic support were directed at the surgeons. ... Some surgeons may not see their role as providing empathic support, or, if they do, may not have the time or skills to fulfil these patient needs. p. 391

Carl Rogers (1957) claimed that there were three important elements of therapeutic relationships, empathy, genuineness and unconditional positive regard. These seem to be important elements of identity support. For Rogers (1980) empathy involved;

entering the private perceptual world of the other and becoming thoroughly at home in it. It involves being sensitive, moment by moment, to the changing felt meanings which flow in this other person. p. 142

Egan (1990) noted that empathy was costly to helpers as they put their own concerns aside in pursuit of the other. Professionals share with informal helpers a need for support for their own identities. Being genuine, involved helpers in being themselves, not overemphasising the helping role, being spontaneous and being consistent by not thinking/feeling one thing and saying another. Rogers (1967) also spoke of respecting the client and suspending critical judgement, terming this 'unconditional positive regard'. Evidence suggests that 'unconditional positive regard' is an important facilitative condition in helping relationships (Wills 1985). However, Shanley (1984) noted lack of support for the hypothesis that empathy, warmth, and genuineness were 'necessary and sufficient' for all successful therapies. He maintained the three factors were facilitative conditions for constructive changes in personality.

Dunkel-Schetter (1984) found that patients desired emotional support, information and advice from medical caregivers, and saw lack of emotional support as cold and rejecting. Ervin (1973) noted that the literature on cancer patients' interactions with caregivers has not always acknowledged that these relationships sometimes become intense and important to both parties. Morse *et al.* (1992) maintained that use by professionals of informal alongside formal support is therapeutic to patients. In a model of nurses' responses to patients, they described four communication

patterns, two being therapeutic (patient focussed) and two untherapeutic (nurse focussed). The first therapeutic pattern consisted of informal responses like pity, sympathy, consolation, compassion, and reflexive reassurance. The caregiver was emotionally involved and identified with the sufferer. The second therapeutic pattern consisted of learned professional responses like therapeutic empathy (learned by rote), emotional empathy (learned by experience), humour distraction, and confronting. The caregivers' emotional involvements with sufferers were more limited than in the first level response and they imagined what it was like for patients rather than becoming genuinely involved in their experience. Morse *et al.* claimed that their model;

expands previously conceived notions of what therapeutic communication should entail. p. 820

However, while patient focussed first level responses are beneficial to patients;

it is not beneficial or desirable to be constantly in an engaged relationship and to be consistently using first level responses. Other types of responses are often appropriate and these may protect the caregiver or be needed by the patient and ideal for the situation. p. 820

Brown and Pedder (1979) also noted that while some elements of psychotherapy are known intuitively and practised by many people, it often requires the relative detachment and socially sanctioned authority of a professional relationship to make them acceptable to those seeking help. Crises are times for self exploration and for developing new identities. A therapeutic relationship can facilitate this. Patterson (1980) argued that the presence of empathy, unconditional positive regard and genuineness lead clients to engage in self exploration, take responsibility for themselves, make decisions and seek necessary information.

The move towards informal support is a question of degree since professionals want to preserve their distinction and distance from clients and the latter have different expectations of professional compared to lay support.

5cii Formal and informal support for relationships

Lichtman and Taylor (1986) noted that female patients with cancer needed to be aware that certain problems in relationships were common, e.g. the occasional rejection by a friend or communication strains with partners. Family and friends needed to know that emotional support was maximally helpful to the patient, whereas information and advice might be unhelpful. They suggested that couples at

risk for sexual dysfunctions might benefit from interventions involving their partners. Husbands might also need opportunities to ventilate private concerns more freely (Cohen and Wellisch 1978). Whilst husbands' minimisation of their own and patients' concerns about cancer was understandable, this might be maladaptive for the patient.

Lichtman and Taylor (1986) reported that families with young children where a parent had cancer, were vulnerable to role conflict and poor family cohesion. Patients counselled that it was not abnormal for problems to develop in their relationships with adolescent and young adult daughters, might be more sensitive to demands they placed on these young women, and might be less upset by any problems arising. Children who were counselled about the importance of their support of parents might attempt to be more supportive in their reactions.

6 Roles of formal and informal support in identity maintenance at different stages of illness.

Mages and Mendelsohn (1979) described a sequence^{of} adaptive tasks around stages of cancer.

6a Suspicion and diagnosis

Mages and Mendelsohn (1979) maintained that at the stage of suspicion and diagnosis, the adaptive task was to appraise the significance of the discovery and initiate appropriate treatment but intense fears of the possibility of cancer, tempted patients to rationalise symptoms. Several researchers have reported this stage of illness to be the most stressful. Northouse and Swain (1989) found that 83% of their respondents reported the prediagnostic phase as the most stressful. Women talked of uncertainty as worse than knowing they had cancer. Fifty per cent of husbands reported the prediagnostic phase as the most stressful.

6ai Informal support

Mages and Mendelsohn (1979) noted that a diagnosis would usually be sought. However, this would frequently be the outcome of an extended process involving indecision and being pushed along by the urging of others.

6aii Formal support

The professional's role would be to diagnose the abnormality and provide the patient with information about it.

6b Treatment

Mages and Mendelsohn (1979) maintained that during primary treatment the adaptive task was to recognise the realities of the situation, regulate emotional reactions and integrate the illness experience with the rest of life. People had to come to terms with physical damage from the cancer or treatment, compensate for lost parts or functions where possible, and maximise other potentials to maintain self esteem and intactness. In studying how women coped with breast cancer, Krause (1987) found that the acute stage of the illness was characterised by insecurity, powerlessness, isolation, fear of death, guilt, anger, depression, even suicidal thoughts (for example, Maguire 1976). Patients' greatest concern was uncertainty about the illness continuation.

6bi Informal Support

In times of uncertainty, comparison with others' situation can provide guidance about coping and progress. Taylor *et al.* (1983) found patients with breast cancer softened the impact of the diagnosis by comparing themselves with others with worse forms of cancer and prognosis. When it came to actively coping with their plight, they made upward comparisons with persons who had overcome their disease, using them as models of effective coping. Van den Borne *et al.* (1987) collected data from patients with lymphoma and those with breast cancer. They found regular contacts between fellow patients decreased negative feelings, feelings of uncertainty and increased self esteem. This was especially true for patients under treatment and those with recurrence.

6bii Formal support

Krause (1987) claimed that information and attitude were factors that helped patients cope. Information was usually provided by doctors and nurses and helped patients understand procedures, get questions answered and know what to expect in hospital. Women also talked about the importance of 'staying positive'. Oberst and Scott (1988) contended that patients with cancer need information to help them formulate expectations for recovery from illness. This would help patients and

spouses anticipate what to expect physically and emotionally as they adjust to illness.

6biii Professionally led or facilitated support groups

Jacobs *et al.* (1983) assessed the effects of patient education and peer support groups on behaviour. Patients with Hodgkin's Disease were assigned to one of four groups, two acting as controls. Education group patients received a booklet about Hodgkin's disease and newsletters about treatment. The peer support group had 8 sessions in which members' concerns were discussed, each attended by an oncologist, social worker and psychologist in non directive roles. This group significantly improved their knowledge of Hodgkin's disease and showed decreased anxiety and treatment problems. Improvement in depression, anxiety, personal habits, interpersonal problems and treatment problems was experienced by both groups.

6c Recovery; convalescence

Mages and Mendelsohn (1979) noted that the adaptive task at this stage was to communicate changed attitudes, needs and limitations. Most patients reported they had been changed by the cancer experience and developed new attitudes toward time, mortality, work, personal relationships and life priorities. They were frequently treated differently by family friends and employers. When the possibility of recurrence arose, the adaptive task was to be able to ignore it most of the time yet remain sufficiently aware of the realities to continue medical follow-up.

6ci Informal Support

The role of informal support at this stage would affirm the patient's identity through emotional support, and encouragement to resume normal roles.

6cii Formal Support

Formal support at this stage would inform the patient of his progress towards recovery by medical monitoring. Frank-Stromborg and Wright (1984) maintained that for optimum quality of life, the focus of patient and family education needs to be on wellness, rather than sick role behaviour and on promoting self responsibility rather than fostering dependence on health care professionals.

6d Recurrence and advanced disease

Mages and Mendelsohn (1979) noted that should cancer recur, the adaptive task was to exercise choice where possible and accept dependence where necessary. A particular problem was maintaining a sense of control over life. In terminal illness, the adaptive task was to prepare to leave family and friends, provide for loved ones, and learn to use medical resources to minimise pain and retain personal dignity. In studying social support among patients with breast or colo-rectal cancer, Dunkel-Schetter (1984) found more problematic interpersonal relationships among patients with advanced cancers than with early stage disease. She suggested that the link between support and well-being might be attenuated under high stress conditions, perhaps because well-being was threatened in multiple ways by a poor prognosis and support could not ward off all the threats.

6di *Informal support*

Bloom and Spiegel (1984) examined the effects of social support on well being and social functioning of 86 women with metastatic breast cancer. Results consistent with previous research indicated the importance of emotional support from significant others in modifying effects of stress on well being, by reducing the perception of pain and depressive outlook. Social activity affected not only psychological health but the level of social functioning by providing greater opportunities for supportive exchange, and was associated with a decrease in maladaptive coping mechanisms such as excessive drinking and worrying. Bloom and Spiegel maintained that the frequently noted erosion of the cancer victim's social support appeared to be caused by illness constricting social activity rather than others withdrawing in response to cancer's social stigma.

6dii *Combined Formal and informal support*

Spiegel *et al.* (1981) studied women with metastatic breast cancer participating in a support group. The experimental group met weekly for a year and every 6 weeks, their relatives joined the group. There was sharing of mutual concerns such as family and doctor-patient relationships but little confrontation. A psychiatrist and leader facilitated group interactions. Participants in the peer support groups reported significantly less tension, depression, fatigue, confusion, maladaptive coping responses and more vigour than controls. Spiegel *et al.* (1981) identified five dimensions of the change process;

1. Patients' discussions clarified problems and identified sources of feelings of helplessness.
2. Group companionship mitigated isolation.
3. Witnessing the death of several participants and airing their fears and grief, members gained strength to confront their own death.
4. The group helped them to consider how they wanted to spend their remaining days.
5. Opportunities to help other group members enhanced their sense of personal worth.

Summary

This literature review explores the essence of social support. Quantity of relationships indicates social integration which gives individuals purpose and meaning in life through shared values. Quality of relationships as shown by intimacy and attachment, provides stability, self worth and security for self exploration. The quantitative approach to measurement of support minimises the importance of individual participation in constructing meanings. The qualitative approach gives little sense of structural influences on provision of support. Social network analysis explores both quantity and quality of relationships. It shows that the essence of support is the maintenance and enhancement of members' identities in social interaction. In illness, identity can change positively with affirmation from network members or negatively because of labelling, blame, avoidance or oversolicitous behaviour from members whose own identities may be threatened by the crisis. Social network analysis indicates what support resources are available to individuals. When certain types of support cannot be supplied within the network, individuals can initiate changes in membership to procure it. Network analysis reveals two conditions under which support is given and received. Reciprocity means that people both offer support to others and require attention from them. Normative beliefs about caring are important in illness, in influencing who provides what type of support. Illness threatens many aspects of social identity. Social support reduces stressors, assists with coping and maintains or changes identity. Formal and informal support have different but complementary roles in assisting coping and adjustment at various stages of the illness experience.

Chapter Two

Method

PART 1

Data Sources and collection

The Macmillan Study's focus was health visitors' role in supporting patients with breast cancer, exploring their knowledge, how they used it and any differences they made to patients' coping ability. There were three data sources;

- Pilot study
- Home interviews
- Macmillan Study

Methods were used as seemed most relevant to different aspects of the research;

- 1 Qualitative
- 2 Quantitative
- 3 Analysis of social contacts/networks

1 Pilot study

Participating patients with breast cancer in the Pilot Study received a variety of treatments as Breast Unit outpatients. The Pilot aimed to identify;

- 1 Important *variables* influencing patients' perceptions of problems and support
- 2 Important *themes* in patients' perceptions of their problems and support

and successively to represent and further explore these variables and themes in the main Macmillan Study.

1a Sample and Method

The pilot sample was convenient, comprising 29 patients attending Breast Unit clinics. Patients were at various treatment stages (including 6 with advanced disease) and having different treatment types. The age range was 34 to 81 years, the average being 54.2 years; 51% had been diagnosed within the previous year with others being followed up longer term. Sample size seemed sufficient to identify trends in patients' responses as the basis for interviews in the main Macmillan Study. Patients attending clinics were interviewed. Biographical information on marital status, occupation and family was obtained, that on age and home district from their case notes. The interview schedule consisted of 12 open ended questions.

- 1 How have you been feeling since your operation/since starting treatment?
- 2 What are your main concerns about yourself at present?
- 3 How are you coping with everyday life? (work, managing the household)
- 4 Are you able to enjoy social contacts? (going out, meeting friends)
- 5 Have you any concerns about your family, relatives, friends?
- 6 How do you feel about your treatment?
- 7 What were you told about your treatment, by whom?
- 8 Would you have liked more information about or support during treatment?
- 9 Have there been difficult times when you have felt miserable or anxious?
- 10 Have you had support from the liaison health visiting service? (If yes, was it helpful?)
- 11 How would you feel about receiving support from the liaison health visiting service?
- 12 What other support have you received in the community, professional or voluntary? Was it helpful?

Lack of time and patients' anxiety at check-ups gave little opportunity for questioning in depth about support from professional and informal sources.

2 Home Interviews

A further group of patients was interviewed at home, where they felt more relaxed, to follow up in more detail, points raised in the Pilot Study interviews and sources of informal and formal support.

2a Sample and method

Tape recorded home interviews were conducted with 18 patients at various stages of breast cancer treatment; 50% were recently diagnosed (1 month-1 year ago), the others having been diagnosed between 13 months and 4 years previously. Five in the latter group, were having treatment for recurrence. In most instances, two interviews were conducted with each patient. Patients' permission was always sought prior to using a tape recorder during interviews and reassurances given about absolute confidentiality.

3 The main Macmillan Study

Initially, an experimental approach was considered for the main Macmillan study, interviewing two groups of patients with breast cancer, one acting as a control. The experimental group would be visited by health visitors, the others would not. The two groups' perceived adequacy of support following hospital discharge would then be compared. This method was abandoned for several reasons. Patients and health visitors were apparently not convinced of the positive value of health visitor visits and the liaison service was not reaching many women included in the survey. A scheme involving health visitors interested in working with patients with breast cancer might be more effective. The large number of patient interviews necessary to form two comparable groups would have been time consuming, have had to be structured and confined to exploring the support provided by health visitors. An incomplete picture of sources and types of patients' formal and informal support would have been obtained and there would have been limited insight into their perceptions of the meaning of social support.

3a Choice of qualitative methods

The research methods discussed in social support literature indicated that a qualitative approach was more appropriate than a positivist approach for exploring the meaning of social support. The phenomenological approach explores the phenomenon's 'essence' by distilling stories of real life experience to get at the meaning they have for people. This approach enables people to describe their experiences and perceptions without imposition of the framework of the researcher's expectations. Oiler (1981) maintained that when nursing's aims were to predict and control, they were better served by the scientific method, whereas the

phenomenological approach was more appropriate for describing lived experience. She noted that nursing was concerned with individuals' experiences such as suffering and dependence. These 'elusive concepts' could be clarified only by attending to them as human experiences. Had I used an experimental approach to the research design, it would have been difficult to have formulated an hypothesis about the nature of social support prior to data collection given the often conflicting evidence in the social support literature.

3ai Grounded theory

My overall approach chosen for data collection and analysis for this thesis was grounded theory as described by Glaser and Strauss (1967). Their central thesis was that theory is systematically obtained from data by inductive analysis, not by logical deduction from a priori assumptions. It is then tested in the field in a deductive way. The process by which grounded theory is generated is known as the constant comparative method by which every element of data is compared with every other. The flexibility of Glaser and Strauss' approach is illustrated by their contention that new perspectives can occur at any time. Strauss (1987) noted that grounded theory was not a specific method or technique.

It is a style of doing qualitative analysis that includes a number of distinct features such as theoretical sampling and certain methodological guidelines, such as making constant comparisons and the use of a coding paradigm to ensure conceptual development and density. p. 5

3aii Interviews

I decided that tape recorded interviews would be effective in exploring the meaning of social support. In line with the grounded theory approach to data collection, initial interviews were largely unstructured, becoming more specific as the research developed. As common themes were identified, further questions were added to the interview schedule. Oiler (1981) noted

Phenomenological inquiry begins in silence. p. 180

She maintained that, since it was impossible to be completely free of bias in reflecting on experience, researchers should control it by 'bracketing.' This meant that to see lived experiences, researchers should suspend what they think they already know about them.

3aiii Descriptive data and statistics

Strauss (1987) suggested descriptive statistics were relevant in qualitative studies. I used these when appropriate. I noted frequencies of patients' different relationships. This later enabled me to compare and contrast various sources of social support or stress. I used demographic data, such as age, marital status and occupational status to profile patients, noting associations with patients' perceptions of support.

3b Samples for the main Macmillan Study

Participants were patients attending the Breast Unit and health visitors.

3bi Recruitment and sample of health visitors

Criteria for inclusion of health visitors in the Research Project were a positive attitude towards patients with breast cancer, a willingness to undertake education for the role and to report on their involvement. There were six administrative areas for community nursing in Edinburgh. Nursing officers for these areas, having circulated the research protocol among health visitors, then asked for volunteers. There were 6 inexperienced volunteers from Edinburgh and 1 from Midlothian with considerable experience in caring for Breast Unit patients.

3bii Recruitment and sample of patients

At the time of diagnosis, all patients were seen by the Breast Unit Nurse Counsellor who discussed their treatment with them, including the availability of the liaison health visiting service. Patients indicated whether they wanted contact with a health visitor after hospital discharge. I then approached some of those wanting health visitor support and requested their participation in my research.

Sampling is relevant to the question of research validity. Hammersley and Atkinson (1983) maintained that in qualitative research the researcher is not looking for representativeness, as in statistical sampling, but for information rich cases. They suggested that in the early stages of generating theory, it was unlikely that choice of cases would matter greatly while in the later stages of testing theory it might be important. In grounded theory designs, the sample can only be identified retrospectively, once the theory has been generated. Individuals are selected to

provide comparison data. Strauss (1987) noted that the basic questions in theoretical sampling were;

What groups or subgroups of populations, events, activities (to find varying dimensions, strategies etc.) does one turn to next in data collection? And for what theoretical purpose? p. 38

He argued that this is not the same as selective sampling where there is a calculated decision to sample according to preconceived dimensions which are worked out in advance.

Following Strauss, I initially selected patients on the basis of criteria which both literature and Pilot Study had indicated as being important influences on their support needs. Further criteria were added as research progressed, as is required by the constant comparisons method. I found that some children had reacted adversely to their mothers' breast cancer and decided to include more patients with school age children in the sample, to test whether these were isolated incidents.

Important to sample size was that health visitors should have sufficient numbers and varieties of patients to demonstrate whether patients perceived their support as effective. It was likely that effectiveness of health visitors' support would increase with experience. To meet these criteria, I aimed to allocate 5 patients to each health visitor. Since some patients needed more health visiting time/support the actual range of patients referred to each was 4-6. The sample of 35, whose participation was secured during an 8 month period from July 1991 to February 1992, consisted of 32 women having various treatments for primary breast cancer and 3 women with recurrence. Since breast cancer largely affects females, male patients were excluded. The selection criteria and sample characteristics are now detailed.

3bii Treatment Groups

Both literature and my Pilot Study and Home Interviews (hereafter referred to as the Initial Survey) indicated that, among patients, major concerns were extensiveness of treatment and its distressing side effects. Much previous breast cancer research concentrated on the psychological sequelae of breast surgery, and not on patients' coping with other therapies. I wanted to explore problems arising from various treatments, how patients coped and what support health visitors offered. Treatment trials for breast cancer are being conducted nationally and there

are various treatment options. Patients having breast conservation have different adjuvant therapies depending upon tumour oestrogen status and axillary lymph nodes spread. Some patients with large tumours have preoperative, systemic treatments. Patients having mastectomies decide whether they want reconstructive surgery. I wanted to explore the support they received in making such decisions. Patients treated solely with Tamoxifen were excluded since the Initial Survey showed such elderly patients sometimes had health and social problems but few had problems with Tamoxifen.

Table 1 shows treatment groups

Table 1		
Treatment Groups N=35		
Treatment Group	Number	%
Wide Local Excision	11	31.4
Mastectomy	12	34.3
Large Tumours	4	11.4
Inoperable Tumours	5	14.3
Recurrence/ Advanced cancer	3	8.6
	35	100.0

Wide Local Excisions (N=11)

In this category, 5 had an axillary node sample performed, and 6 an axillary node clearance. Two needed further surgery, one having a mastectomy.

Mastectomies (N=12)

Of these, 2 patients had bilateral mastectomies and 5 had breast reconstruction.

Large Tumour Treatments (N=4)

These women had several weeks of hormone treatment (Zoladex) prior to mastectomy, three also having oophorectomies. Three had breast reconstructions.

Stage of Disease.

The literature and my Initial Survey described how most patients with breast cancer feared recurrence, since treatment did not guarantee cure. Weisman and Worden (1976) called this situation 'the existential plight in cancer'. In my Initial Survey, anxiety about the future was even more apparent in patients with advanced than with early breast cancer. These women had difficulties in coping with problems arising from their illness, had curtailed social lives and little peer group support.

I decided to include in the sample some patients recently diagnosed with inoperable disease and some with recurrence. I wanted to discover whether they had special support needs and whether health visitors were the most appropriate support sources. Four health visitors were allocated such patients.

Inoperable Tumours (N=5)

These patients had all been recently diagnosed with inoperable local or metastatic disease. The first had intensive chemotherapy, the second, hormone therapy followed by radiotherapy, the third, hormone therapy, intensive chemotherapy and radiotherapy and the fourth, hormone therapy alone. The fifth patient who developed further metastases following initial diagnosis had hormone therapy followed by chemotherapy.

Recurrence/Advanced Cancer (N=3)

These patients had developed recurrences of their initial breast cancer, diagnosed some years previously, and were receiving palliative treatment. Two had had radiotherapy while the third was receiving chemotherapy.

Demographic Variables

Literature indicated that social support was influenced by demographic factors. In a research review, Vaux (1985) noted;

Variations in levels of social support are at least partly the result of cultural norms regarding appropriate behaviour for individuals of a particular age, gender, socio-economic status or ethnicity. p. 90

Vaux also noted that the context in which social support operated, varied across subpopulation groups and that differing demands required different resources. In a study of women treated with mastectomy, Metzger *et al.* (1983) found that sexual

dysfunction was more problematic for younger, divorced or separated women than for married, widowed, or never married women in the same age group. However, in a study of the relationship between age, type of surgery and psychological distress, Fallowfield (1991) found that assumptions that elderly women did not mind losing a breast were not supported since when given a choice, the majority opted for lumpectomy rather than mastectomy. Thus I wanted to include women of various ages and marital status in my sample.

Age

It seemed likely that women of different ages with breast cancer might experience different stresses and seek support from different sources.

The sample's age distribution is shown in Table 2; ranging from 28 to 75, with a mean of 50.8 years.

Table 2

Age Distribution		
Age Range	Number	%
30 or under	1	2.9
31-40	6	17.1
41-50	9	25.7
51-60	13	37.2
Over 60	6	17.1
	35	100.0

Marital Status

My Initial Survey indicated that family members were primary sources of support for most patients. Husbands were not always the main support for married women, who sometimes chose mother, daughter or sister as confidants. Widowed and divorced women received support from family members such as adult children. The Initial Survey had included only a few divorced (4), widowed (9) or single women (5) and it was hoped to include more of these in the main Study to explore differences in support patterns. I succeeded in this aim in relation to widowed and divorced but could only recruit one more single woman. Most women were married

(N=23,66%),1(3%) was single, 8(23%) were widows and 3(8%) were divorced or separated.

Children

Of the 28 women (80%) in the final sample who had children, 8(29%) had at least one child of school age and the remaining 20 (71%) had adult children.

Occupation and Social Class

It is known that employment can be supportive financially and in terms of self-esteem, interest, and companionship of work colleagues. In a Canadian study of the effects of social relationships on survival for women with breast cancer, Waxler-Morrison *et al.* (1991) found that having employment was statistically important for survival. Their respondents received support from work colleagues. They often worked with other women and when their colleagues discovered they had breast cancer, they gave information about the disease from their own or acquaintances' experiences. Waxler-Morrison *et al.* posited that having a job reflected some aspects of choice and control. Women who worked were significantly more likely to have a large family income, providing opportunity for the kind of choices that lower income or unemployed women might not have. In my Initial Survey, many women reported receiving support from work colleagues and they were eager to return to work. Two of the six women with advanced cancer in the Initial Survey worked full time. I decided to include women in a variety of occupations to note the effects of employment (and social class) on perceptions of support. Table 3 shows patients' employment status.

Table 3

Employment Status N=35		
Employment	Number	%
Employed full time	15	42.9
Employed part time	8	22.9
Retired	6	17.1
Housewife	5	14.3
Unemployed	1	2.8
	35	100.0

All employed women had had several weeks sick leave because of their breast cancer treatment. Occupations of employed women are shown in Table 4.

Table 4

Occupation N=23		
Type of occupation	Number	%
Professional	5	21.7
Own Business	1	4.3
Clerical	8	34.8
Semi-Skilled	3	13.1
Sales	1	4.3
Catering	2	8.7
Cleaning	3	13.1
	23	100.0

Middle and lower income groups are well represented. The professional group included 3 nurses, a social worker, and an administrator. The semi-skilled group included a bus driver, a barmaid and a nursing auxiliary.

Ethnic Group

I hoped to sample patients from different ethnic groups but few such women attended the Breast Unit during the research period. Only one non-Caucasian patient was recruited. I interviewed a young Chinese woman but she did not wish to see a health visitor. My study proved unable to address the support needs and patterns of ethnic minority groups.

Area of Residence

I wanted to explore differences in support perceptions of patients in Edinburgh and those living outside the city. Did those outside the City keep in touch with peers as much as those within it? Twenty eight patients lived in Edinburgh, 4 in Bonnyrigg, and one each respectively in Dalkeith, Gorebridge and South Queensferry.

Concurrent Illness or Disability

I was interested to explore whether having an illness concurrent with breast cancer influenced women's support needs. Twelve women (34%) had a concurrent illness or disability. Three had hypertension. Other complaints included angina, arthritis, bronchitis, asthma, cervical spondylosis and deafness. These illnesses/disabilities only caused major problems in one instance.

Previous Experience of Breast Disease

Given the negative public image of breast cancer, I wanted to discover the effects of a breast cancer family history on respondents' coping and their perceptions of support. Eight women had such a family history but among these, 6 had relatives who were well following treatment, presenting positive role models. Most women knew of someone who had had breast cancer. Two women had negative family experiences of breast cancer and 6 women had negative family experiences of other cancer types.

3biii Preparation and education of health visitors

The seven health visitors who had volunteered to participate discussed the research plan with me. I decided that prior to visiting patients, they should undergo a short, basic education programme on breast cancer care. This programme aimed to improve their supportive skills in key areas (Appendix 2). I provided further opportunities for updating during the research through journal and other information, a Study Day on breast cancer care and a visit to the new Breast Unit transferred from Longmore Hospital to the Western General Hospital, Edinburgh. If the health visitor liaison scheme were to continue on completion of my research, regular updating would be important because of changes in treatment protocols and the anxiety in patients prompted by constant media coverage of breast cancer.

As the health visitors' experience of breast cancer care was variable, I constructed a questionnaire to help them to identify areas of individual knowledge, skills and attitudes on which to focus during the education programme (Appendix 3). The questionnaire was completed by the health visitors at the outset and conclusion of the research, the aim being to compare their perceived levels of knowledge, skills and confidence in breast cancer care before and after a nine month period of education and experience.

3biv The health visiting intervention

Telephone referrals were made to health visitors by the Liaison Health Visitor who met regularly with the Breast Unit Nurse Counsellor. The latter provided information about patients recently discharged home. Some patients were referred for a second time because of new problems. I designed a Discharge Form to back up telephone referrals. This reported patients' diagnoses, treatment plans and relevant personal information (Appendix 4). I originally arranged for the Discharge Form to be filled in by Breast Unit nursing staff but as there were difficulties in ensuring adequate completion, I did this myself. The Director of Community Nursing Services estimated that health visitors would have time to conduct one weekly visit to patients with breast cancer additional to normal caseloads. Some patients selected required more frequent visiting than others. This was taken into consideration in allocating patients to individual health visitors. In selecting patients, I also considered their home areas, so that similar numbers of patients could be allocated to each health visitor.

One of the research questions in relation to health visitors' support had been 'What is the optimum visiting schedule?' Other commitments placed a constraint on the frequency of health visitors' contacts with patients with breast cancer. Whenever possible, I aimed at the number of visits made to patients being a response to their wishes. Thus I hoped to gain a better idea of the demands patients would place on health visitors' time than if frequency of visiting had been decided in advance.

Visits were designed to assess patients' physical and psychological adjustment to breast disease, using Domiciliary Assessment Forms (Appendix 6) adapted from a design by Tait *et al.* (1982) and to discuss whatever concerns patients raised. If patients had difficulties, health visitors would provide appropriate information and support or, if unable to do so, would refer them to appropriate sources of help. The health visitors would also be available to support patients' family members.

3bv Monitoring and evaluation of the health visiting intervention

This was done in six ways;

- a Interviews with health visitors
- b Interviews with patients
- c Patients' diagrams of their social networks

- d Health visitors' diagrams of patients' social networks.
- e Health visitors' diaries
- f The Domiciliary Assessment Forms

a Interviews with health visitors

I conducted tape recorded interviews with each health visitor 2-3 months into the intervention period and again approximately 8 months later. The interviews aimed to find out how health visitors coped with additional patients in their caseloads, their attitudes towards their new role, and their levels of confidence in their knowledge and skills in caring for patients with breast cancer. They were asked to identify key problems encountered among their patients and the type of support given or planned in each case. The problems identified by the health visitors were compared with those identified by me in my interviews with the patients. The extent of agreement between the 2 sets of observations was then examined. During my interviews with the health visitors, I asked them about the following aspects of their new role;

Management of their caseload

Attitude to their role in supporting patients with breast cancer

Feelings about their preparation for the role (knowledge, skills and confidence)

Support received from health visiting colleagues

Support received from health visiting managers

Effectiveness of hospital community liaison (information received about patients, contacts with hospital staff etc.)

b Interviews with patients

I conducted two tape recorded home interviews with each patient soon after her referral from the Nurse Counsellor and again 2-3 months later when the health visitor would have visited. Interviews followed the grounded theory policy. I started with general, open ended questions and progressively added further questions as themes emerged from previous interviews. Patients were asked whether they had problems, how they were coping and what professional and informal support they were receiving. Interviews were transcribed and coded.

Social network analysis seemed a promising way of supplementing the knowledge gained from interviews.

The literature on social networks indicated that time would not permit conventional analysis, examining all social ties and interviewing all network members. Acock and Hurlbert (1990) noted that it was often impractical to gather total information on networks. They focused on 'egocentric' networks defined from the perspective of the focal individual, 'ego'. I decided to adopt this approach. After a patient interview, I asked her to draw her social network with herself at the centre. I then asked her about her relationship with each named individual and her perceptions of support received or strains within the relationship since her diagnosis (Appendix 5).

The way in which names of network members are generated determines network boundaries and possibly other network measures such as density, and proportion of kin. Acock and Hurlbert (1990) maintained that name generators should be as specific and salient as possible, consistent with research goals. I aimed to meet the criterion of specificity by relating name generation to the onset of the patients' illness and the criterion of saliency by asking patients to draw the network diagrams immediately after interviews when I had discussed with patients their network members' reactions to the illness. I asked patients to include all people (kin, friends, neighbours, peers, and professionals) with whom they had been in contact since diagnosis. I then asked them to describe ways in which the included people had reacted to the illness (supportive and non supportive behaviours) noting this down at the foot of the diagram. I found that patients sometimes included in their network diagrams people whom they had forgotten to mention during my interviews with them. I hoped to obtain the following information from patients' network diagrams.

I noted ways in which different types and sources of support related to each other in patients' perceptions. I asked patients what kinds of support they had received from professionals, and from informal sources. I analysed my interviews with the patients and their diagrams of their social networks, focusing particularly on informal relationships.

Patients represented diagrammatically the balance of support and stress within their networks presenting a more total picture than would have been possible through

interviews alone. Stewart (1989) maintained that nurse researchers should address negative as well as supportive interactions.

Social support measures ... should distinguish between network members who provide only positive forms of social support and those who are sources of negative interaction and examine the overall balance of sustaining and discordant influences. p. 271

To elicit comments about negative and supportive behaviours I asked patients about network members' reactions to their illness rather than about support received from them. Patients mentioned network members' negative as well as positive (supportive) reactions and instances when they had not received the support they expected.

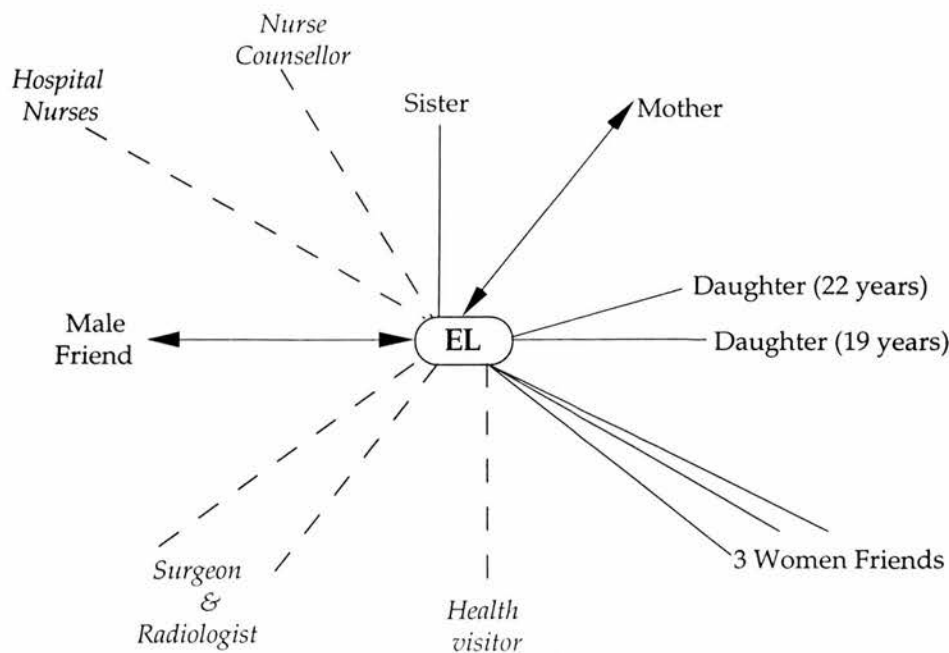
Network diagrams showed changes in membership since diagnosis, for example lost relationships, new relationships, and reactivated relationships. I noted the proportions of formal and informal support and whether those with less informal support needed more professional support. Where patients placed professionals, particularly health visitors relative to themselves and other network members in their diagrams, indicated the relative importance of that support.

Diagrams showed network size and how this related to patients' perceptions of support. The average number of people whom patients portrayed in their network diagrams was 21, the range being from 13 to 31. Examples iva and ivb show a small and a large social network respectively. Differences in size of the two networks seemed to be due to factors unrelated to illness.

Network example 1

EL's network was fairly small. She was divorced but had a male friend. Her family was small. Her 2 adult daughters lived at home and gave some support. Her mother required support because of illness. EL was unemployed and therefore had no work contacts. She was not involved in any community organisations. She told her health visitor that she felt 'lonely.'

Network example 1
A Small Network (EL)



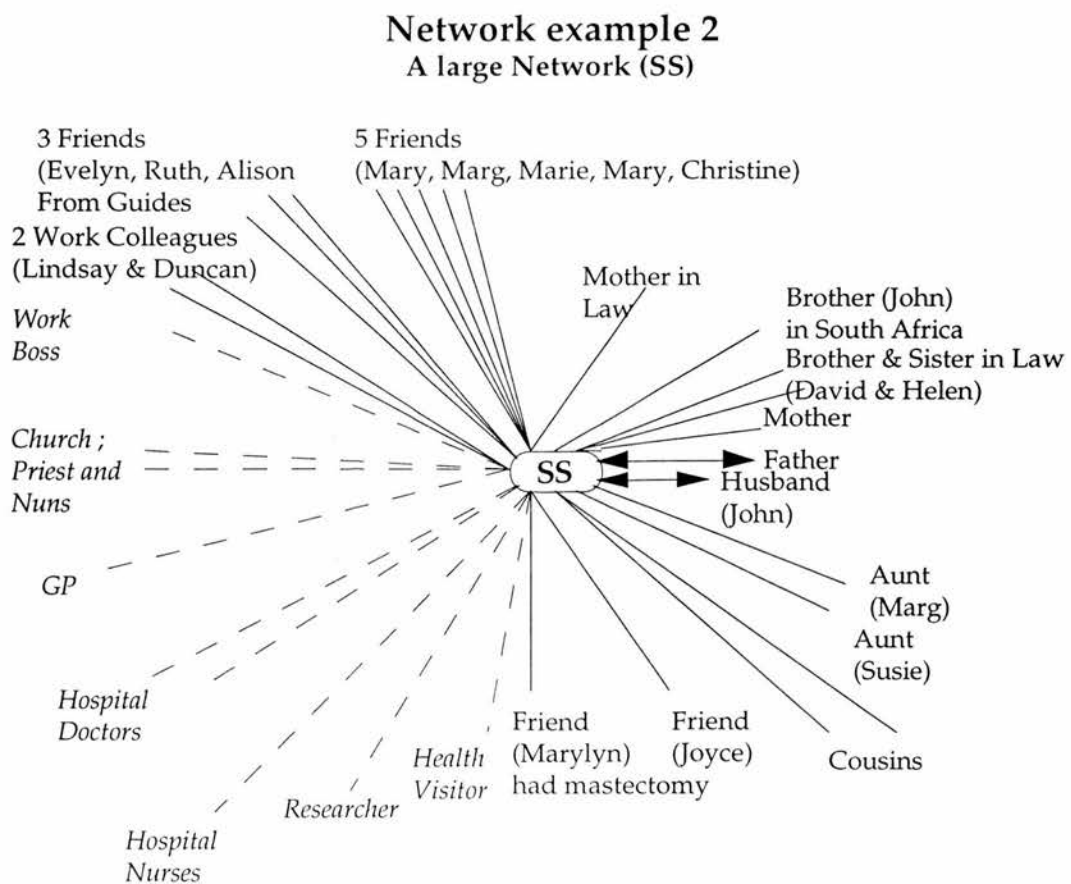
Total Network Size = 13
Formal Support =5
Mother requires support because of illness

- Key
- Shortest lines = Closest relationships
 - Informal Support
 - Formal (Professional) Support
 - Mixed relationship (Offers support and strain)

Network example 2

SS had a large social network. She had no children but a large, extended family. She mentioned 9 friends and had work colleagues through 2 part-time jobs. She had longstanding involvement in her church and the Guide movement. Although she was concerned about her husband's and her father's health, her network members were mainly supportive.

Diagrams showed how patients perceived professionals, and especially health visitors fitting into their social networks and the kinds of support they provided.



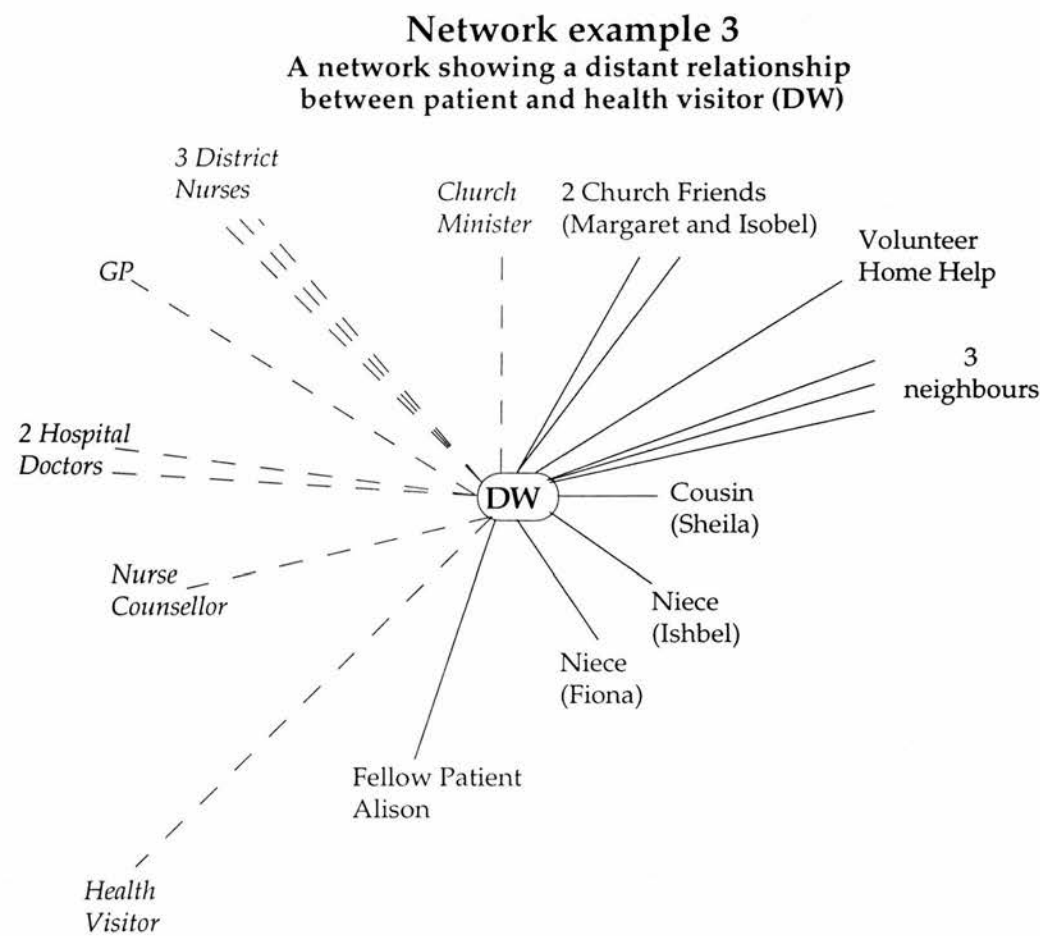
Total Network Size = 32

Formal Support = 9

Key	—————	Shortest lines= Closest relationships
	—————	Informal Support
	- - - - -	Formal (Professional) Support
	↔	Mixed relationship (offers support and strain)

Network example 3

Example 3 shows the patient placing the health visitor distantly from herself. DW was a widow but had received much support since her illness from her cousin and nieces. She had also had professional support from district nurses from her local medical practice. In this situation, the health visitor did not play an important role, although DW was glad of her visit and interest shown in her well-being.



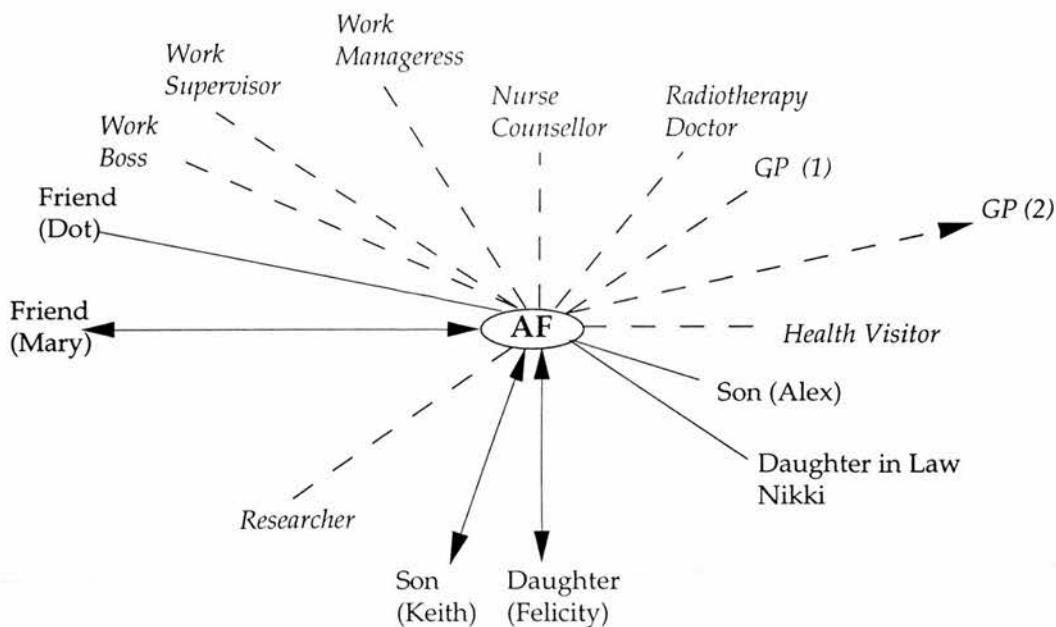
Total Network Size = 19
Formal Support = 9
All relationships supportive

- Key ————— Shortest lines = Closest relationships
 ————— Informal support
 - - - - - Formal (professional) support

Network example 4

Example 4 shows the patient placing the health visitor in close relationship to herself. AF, a patient with advanced cancer described her health visitor as being 'at the hub' of her social contacts. AF had several negative relationships within her network and only two friends who were not close. As she was very frightened by her prognosis, she needed support and seemed to find it in the health visitor.

Network example 4
A network showing a close relationship between patient and health visitor



Total Network Size =15

Formal Support = 9

Mixed relationship with son (Keith) and daughter (Felicity) and friend (Maureen).

No support from GP (2)

Key

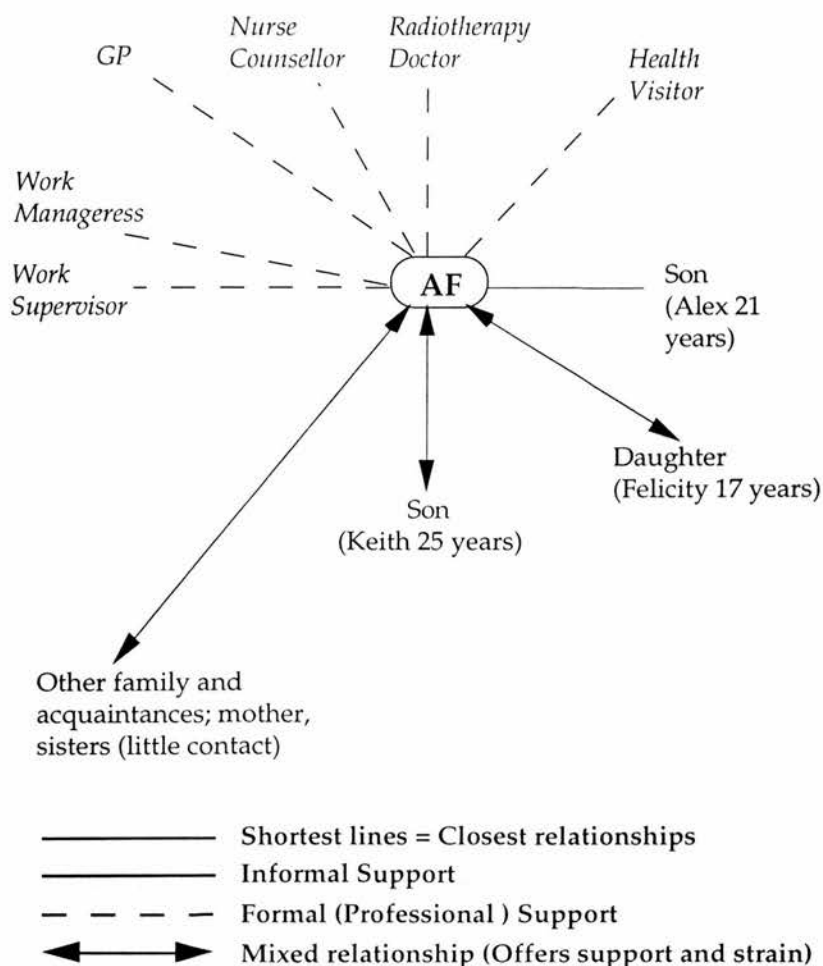
—————	Shortest lines = Closest relationships
—————	Informal Support
- - - - ->	Stressful relationship (Relationship requiring attention from AF)
- - - - -	Formal Support
<====>	Mixed relationship (support and strain for AF)

I also asked health visitors to draw their patients' networks, including themselves, enabling them to more clearly discuss how they viewed their roles when compared and contrasted with the support others provided.

Network example 5

Example 5 shows health visitor (JP's) diagram of patient (AF's) social network and JP's perception of her role in relation to that of other network members in supporting AF.

Network example 5
A health visitor's perceptions of a patient's (AF's) network and her own role within it. (Compare with Example 4)



Health visitor's perceptions of relationships of network members to patient.

Son. (Alex) - Closest family member. Gives practical support.

Daughter (Felicity) Mixed relationship. AF worries for her.

Son (Keith) Mixed relationship. He gives a little support but erratic.

Other Family Members. (Mother, Sisters). Very little contact.

Work Supervisor and Manageress. Both supportive. AF has told them of her illness.

GP. Supportive when necessary. A familiar person over several years.

Hospital Radiologist and Nurse Counsellor. Supportive regarding medical care.
Health Visitor. Non directive counselling, practical help, support for family members, accessibility.

Health visitors' and patients' perceptions were compared, especially regarding kinds of support provided by health visitors and how this complemented support from informal sources.

In comparing patient, AF's, diagram (example 4) and health visitor, JP's, diagram (example 5), it can be seen that JP has not placed herself quite as close to AF as AF has placed her. JP saw her relationship to AF as 'almost' that of a friend. JP's perceptions of the extent of AF's support within her network is similar to AF's. JP has noted the mixed relationships between AF and her daughter, F. and son K., seeing son A as the closest family member.

d Health Visitors' Diaries

I gave the Health Visitors diaries to record the events of each visit to patients and their comments on interactions with patients. They were comprehensively completed by a minority of 3 of the 7 health visitors in the study while a fourth also made some notes. I used the completed diaries to gain further insights into health visitors' perceptions of patients' coping and the nature of relationships between health visitors, patients and family members. Two health visitors also recorded their feelings about visits to patients.

e Patients' Domiciliary Assessment Forms

Health visitors completed Domiciliary Assessment Forms for all patients visited. These (Appendix 6) recorded patients' physical and psychological states and any changes over the period of the health visitors' visits. The form is based on research findings on support needs of patients with mastectomies and has been designed and tested by Tait *et al.* (1982). It was used by me with Ann Tait's permission. The Form was accompanied by guidelines for its completion and was used as an interview guide for health visitors when visiting patients. However, the Health Visitors allowed patients to talk freely about their feelings and about any problems which they wished to raise.

PART 2

The focus of this thesis

This thesis focusses on the nature of social support. I wanted to explore theories about it and to find out how it worked in practice from perceptions of patients with breast cancer. In the Macmillan study, I had focussed on the nature of formal support, particularly health visitors' support to patients. I now wanted to explore their perceptions of informal support from their families, friends, peers, and work colleagues.

1 Data sources

For this study I had old and new data sources and I employed these to explore the phenomenon of social support from different perspectives.

1a Old Data Sources

I had data from the Initial Survey and main Macmillan Study.

1b New Data Sources

Although I had retrospectively analysed data to explore changes in support patterns over the course of patients' illness, I also needed follow up data. This was obtained by further interviews with 10 patients, on average, 12.5 months after the initial interviews. The range of time between first and final interviews was 9 months-12 months. In the follow up interviews, I observed changes in network members' behaviour as patients completed treatment and were perceived as 'getting back to normal'. I observed phasing out of formal support as patients moved towards recovery. I noted changes in patients' attitudes towards their problems and their support needs over this time. Some returned to work and most resumed their usual roles at home and in their community. As the condition of one patient in the follow up group deteriorated, I was unable to interview her.

2 Research methods

Data had been gathered to meet the aims of both the Cancer Relief Macmillan Fund Project and this thesis. The wealth of data I had obtained from the interviews with patients and health visitors and the vast literature on social support at first seemed overwhelming. I devised the following ways of dealing with it.

2a Retrospective analysis of 'old' data

Grounded theory (Glaser and Strauss) is typified by concurrent activities of data collection, organisation and analysis. I had already collected data for the thesis during the Macmillan Study, but I was unable to concurrently analyse it. I therefore adapted Glaser and Strauss method to conduct a retrospective analysis of all my data throughout the life of the research project. The more positivistic research approaches do not allow the use of old data for verifying hypotheses, thus cutting out potential dividends from this procedure. I collected and coded my data, noting within it diverse themes on the nature and effects of social support. I used the literature on social support as another data source, collecting and analysing it by the constant comparisons method.

2b Analysing discourse

My method also employed some techniques of discourse analysis in that I analysed patients' statements to gain insight into their perceptions of social support (Appendix 7). Potter and Wetherell (1987) maintained that discourse analysis can claim priority as the means of displaying social construction processes in action, their context dependence and their variability. West and Zimmerman (1985) reached a similar position regarding the future of research in the language and sex roles area. Coupland *et al.* (1991) used discourse analysis to study identity as a dynamic, interactionally achieved process rather than as a static, intra-individual construct. They studied ways in which individuals introduced and formulated age-identifying statements and modified them in relation to actual or anticipated reactions of others in sequences of speech. Discourse analysis can also demonstrate links between macro issues like cultural perceptions of sexual identity and micro issues such as patients' perceptions of how their sexual identity is compromised by breast surgery. Drass (1988) used discourse analysis to show how the macro issue of differences in occupational perspective could be incorporated into micro studies of the form and content of talk. He identified differences in the interactive strategies

employed by a nurse practitioner and two physician assistants in their encounters with patients. Generally, the nurse practitioner, in both the form and content of her discourse, displayed greater sensitivity to subjective understandings and experiences of her patients in all phases of the encounter.

3 Validity; Problems and Solutions

Field and Morse (1985) defined validity as the extent to which research findings represent reality. Is there such a thing as an ultimate reality? The following factors compromise validity of research findings.

- i Difficulties in establishing truth and reality.
- ii Researcher bias.
- iii Difficulties in generalising research findings to other contexts.

3a Difficulties in establishing truth and reality

Qualitative research has been criticised on the grounds that it may be subjective. However, Silverman (1985) maintained that what goes on in each research setting must be understood in its own terms. If competing versions of a situation are provided, the researcher's role is not to adjudicate which is true but to attempt to understand the situation.

With regard to social support, Depner *et al.* (1984) noted that to establish internal validity the researcher should be able to claim that the variation observed in the measure of strain is attributable to the hypothesised effects of stress and support, rather than some biasing factor. They noted that;

In order for the criterion of internal validity to be met, the researcher should be able to offer two forms of evidence, that exposure to the stressor results in greater strain and that the availability of support reduces the damage. ... The social support study should be based on solid evidence of a stress-strain relationship. Specific knowledge about the nature and timing of the stress process facilitates the development of hypotheses about the way in which support may intervene.
p. 43

During my data analysis, I hypothesised that women needed social support to maintain or make changes to their identities when these were threatened by breast cancer. I had first to establish that patients perceived their identities as threatened in various ways by the illness. I had then to show that they perceived social support as intervening between threat and identity to maintain or change it. I also

explored patients' perceptions of negative (non-supportive) interactions with their network members to provide evidence that patients perceived threats to their identities as increasing when support was not given.

Interviews have been criticised as a research technique for failing to directly evaluate the non interview setting. Stimson and Webb (1975) noted that, when interviewed, patients were likely to tell stories casting themselves in a favourable light. These stories had an unknown relation to what they expected or did in the situations they described. However, Silverman (1985) maintained that interview data is relevant, and that the way forward was to concentrate upon the moral and cultural forms that interviews displayed. He noted that interviews offered a rich source of data, providing access to how people accounted for both troubles and good fortune. Only by following misleading theories of truth could it ever have occurred to researchers to treat interview statements as accurate or distorted reports of reality. They were simply real.

Hammersley and Atkinson (1983) maintained that researchers might miss the effects of temporal cycles by studying phenomena at a single point in time. Conclusions might be invalid for other settings or at other times. In a review of social support instruments created by nurse investigators, Stewart (1989) noted that many stressful situations had different phases requiring different forms of support. She argued that;

... the evolving process of the interaction of stressors and support over time should be reflected more in nursing and the social-psychological literatures on social support. Increasing inclusion of duration in instruments seems desirable.
p. 269

Silverman (1985) also noted that analysing data over time gave an invaluable additional perspective. O'Reilly (1988) noted that support is not easily measured prior to a crisis. When it is measured retrospectively it is subject to the biases of this type of research. He maintained that longitudinal data would be more appropriate than cross sectional data in social support studies since attitudes and behaviour are revealed in process in relation to status passages, rather than fixed to a particular role.

To explore the interaction of stressors, identity and social support over time, I conducted 2/3 interviews with each woman in the main Macmillan Study. I also conducted 10 follow up interviews over a year after my first contact with them.

Data from women in the Initial Survey also illustrated the possible effects of time on these interactions, some being at the beginning of treatment, while others were attending long-term follow-up clinics (see Table 5)

Table 5

Time perspective on support (Home Interviews)	
Time after diagnosis when interviewed	Number of patients
3 months	4
4-9 months	3
1 year	3
2-3 years	4
4-5 years	2
12-18 years	2
	18

Silverman (1985) noted that one strategy for establishing validity of qualitative research was the search for non-conforming cases and displaying enough data for the reader to form alternative interpretations. In my research, I coded all data to identify any deviant cases and to allow for alternative hypotheses.

3b Researcher Bias

The gathering of information by one person is open to the criticism of bias. In qualitative research techniques, the observer may influence the research setting.

Hammersley and Atkinson (1983) argued that, far from limiting study validity, the researcher's involvement, if recognised, could be exploited to yield additional insights. They maintained It was impossible to make the researcher a 'neutral vessel of cultural experience'. Oiler (1981) noted that in striving to contact and uncover the perspectives of people who were living through an experience, the researcher became involved. This involvement could be exploited.

Because the researcher is involved, a range of modes of awareness can be used in data collection. Empathic and intuitive awareness, for example are deliberately and purposefully employed. p. 179

In a study of patients with breast cancer, Cannon (1989) felt her research success depended on being able to form relationships with respondents, gaining their confidence and trust. This required some emotional input on her part. Some respondents categorised her as a friend, others as an additional source of support, some as a counsellor and others simply as someone to whom they could talk.

I was conscious that my presence would influence my interviews. However, to obtain the information I wanted from the women I had to gain their trust. One strategy for avoiding researcher bias is feeding back understandings to respondents to test the adequacy of the researcher's interpretation. Thus, Cannon (1989) devised a way of actively involving her respondents, entailing discussing interviews with the women so that interviews emerged as a collaborative effort. I tried to gauge how I might have influenced the setting by asking respondents to place me within their drawings of the social networks. I discovered that some respondents grouped me with the health visitor, as someone to talk to who was also a source of information. Others saw me as their means of introduction to the health visitor and yet others as having knowledge of breast cancer and its treatment.

3c Lack of applicability to other contexts

A criticism often levelled at qualitative research is its situational nature precluding duplication and applicability of results to other contexts.

My hypothesis about social support maintaining and changing identity was applied mainly to women with breast cancer but I also examined ways in which support maintained the professional identities of health visitors when threatened by their initial inexperience, lack of knowledge of breast care and patients' high expectations of them. Additionally, I explored patients' perceptions of how the identities of some network members were threatened by their illness.

4 Reliability

The findings of research are said to be reliable when another researcher could produce the same results, using the same methods, and when the study could be replicated later with the same results.

Glaser and Strauss (1967) and Stern (1985) have argued that reliability can be established by taking findings back to respondents who provided the original data

from which the theory was generated. Respondents can then confirm or refute the developed theory.

I used network diagrams to increase the reliability of interviews with patients in the main Macmillan Study. After each interview, I asked the patient to draw a network diagram. I then discussed with her the types and sources of support which she had mentioned in the interviews in relation to the network members included in the diagram. In 14 instances, patients included in the diagram a network member not mentioned at interview. In 10 cases, the addition was a source of support, in 4 cases, a source of stress. These included sisters, friends, ministers/priests. Network diagrams were also used as opportunities for patients to confirm or refute what they had said during interviews. When patients were followed up longer term, they were asked about any network diagram changes since the previous interview.

PART 3

Data Analysis

Hammersley and Atkinson (1983) state it is the function of developing and testing theory which distinguishes social research from journalism and literature. Strauss (1987) noted that in grounded theory, analysis was synonymous with interpretation of data and occurred at various levels of abstraction and systematisation. At the beginning of a research project, qualitative analysis was often implicit. Later, conclusions could be drawn more explicitly and systematically.

1 Concurrent collection and coding of data for the main Macmillan Study

During the Initial Survey and the main Macmillan Study, I had concurrently collected and coded data from the following;

- Transcripts of Pilot Study interviews
- Tape recorded interviews with patients (Home Interviews and Main Macmillan Study)
- Tape recorded interviews with health visitors
- Health visitors' network diagrams

Initial, transcription and coding of tape recorded material was manual. Computer purchase assisted me greatly in organising my qualitative data. However, having already manually transcribed and coded a great deal of data, I did not consider it worthwhile purchasing a computer programme to help with further data coding.

2 Interviews with patients

The Macmillan Study focused on the effectiveness or otherwise of health visitors' support of patients with breast cancer. Analysis began by coding patients' reported anxieties and problems since diagnosis, then coding patients' perceptions of sources and types of support they received in relation to their anxieties and problems, concentrating initially on health visitors' support.

2a Patients' anxieties and problems

The interview transcripts furnished lists of anxieties and problems mentioned by each patient. I then compared problems mentioned by patients in the first interview with those reported subsequently, noting progress, deterioration or any new problems mentioned in the second or third interviews and any support mentioned by patients as alleviating them. Initially, I simply grouped problems as;

- 1 Medical
- 2 Psychological
- 3 Social

To gauge the accuracy of the health visitors in identifying patients' problems and anxieties, I recorded any problems mentioned by the patients which had not also been mentioned in my interviews with their health visitors and problems noted by health visitors but not raised in my interviews with the patients.

2b Sources and types of support (formal and informal) for patients

After transcribing the interviews, I noted sources and types of support both formal and informal mentioned by each patient. I defined supportive relationships as 'giving attention to the patient'. I noted support given to patients by family members, friends, neighbours, work colleagues, peer group members and by health visitors and other professionals (GPs, hospital medical and nursing staff, clergy).

2c Sources of strain for patients

I noted patients' comments describing relationships which were not wholly supportive or caused them strain. I described these relationships as 'requiring attention from the patient'.

3 Interviews with health visitors

I coded my interviews with the health visitors under the following headings.

- 1 Management of caseload. How well they coped with extra work incurred by their new role.
- 2 Attitude to role. Perceptions of their new role in relation to other aspects of their work.

- 3 Preparation for role. Perceptions of adequacy for their new role, in the areas of skills, knowledge and confidence.
- 4 Aims of support for individual patients.
- 5 Perceptions of patients' network relationships since diagnosis
- 6 Perceptions of patients' ability to cope with illness and treatment and if this was related to the support given by health visitors.

Interviewing health visitors at the beginning and end of the research period, I could compare responses at each interview and monitor changes in their attitudes and feelings.

3a Health visitors' perceptions of patients' network relationships since diagnosis

I examined health visitors' diagrams of patients' social networks for the following;

- 1 Patients' sources and types of support
- 2 Sources of strain for patients from network members
- 3 Health visitors' perceptions of their position in patients' networks
- 4 Health visitors' perception of their role in supporting patients (e.g. types of support needed and given)

I noted health visitors' perceptions of patients' relationships, both formal and informal, positive and negative. From these I described health visitors' perceptions of the level of support and strain received by each patient. I later compared patients' and health visitors' perceptions. I noted health visitors' perceptions of their own position and role in patients' social networks.

4 Themes from the main Macmillan Study

Several themes emerged from the interviews and literature, during the main Macmillan study.

4a Themes from interviews with patients and health visitors

I grouped types of support and strain mentioned by patients in the interviews. These groups included the following types of support;

Formal Support

Appraisal of symptoms/progress
Appraisal of coping
Availability
Decision making support
Practical
Confiding
Problem solving
Information
Concern

Informal Support

Comparison with peers/role modelling
Emotional
Spending time with/companionship
Affirmation/acceptance
Practical
Confiding
Help with decision making
Sexual identity support

4b Themes in the literature

Benton (1991) argued that in grounded theory method, an in depth critique of the literature prior to data collection and analysis should not be undertaken since this might provide a framework including inappropriate or incomplete categories. Literature should be treated simply as another data source and examined, coded and analysed. Literature should be compared with developing theory and used to support it.

Analysis of data from the interviews and networks proceeded in tandem with literature analysis, looking at;

Patients' coping during illness.

Sources and types of support.

Social networks and social support.

Differences and similarities between formal and informal support.

Definitions of social support.

The literature search was continuous with data collection. Theory was built up initially in an inductive way from what emerged from the data. As categories describing social support emerged, these led to a search, evaluation and selective pursuit of further avenues for exploration in subsequent interviews.

5 Retrospective data analysis and interpretation

Having coded and analysed data relevant to health visitors' support of patients in the main Macmillan Study, I now shifted my focus to this thesis where I wished to explore the nature of social support. I began a retrospective analysis of data from the main Macmillan Study, concentrating this time on patients' perceptions of informal support.

5a What kinds of interaction did patients describe as supportive and what did this say about the nature of support?

I had information on which kinds of interaction patients described as supportive. I compared my findings with the literature; that on social support described various types of support-social integration, intimacy, esteem, companionship, material support, information, problem solving. From patients' diagrams, I knew the size of their social networks, so I noted the relationship between network size and quality of support. I asked;

- (a) Were there common themes underlying different types of support patients described?
- (b) Did types of supportive interaction change over time as patients' health improved or deteriorated?
- (c) Were types of available support matched to types of support sought by patients or were there gaps in support?
- (d) Was support perceived by patients to be a series of interventions or a person to whom they had access?
- (e) What was the relative importance to support of closeness of peoples' relationships and number of their social relationships?

5b Did types of support given vary with their sources?

I also asked;

- (a) Did people in different relationships with patients give different types of support?
- (b) How did patients describe types of support given by kin, peers, friends, neighbours and work colleagues?

5c Were patients active in constructing and using supportive relationships?

Acock and Hurlbert (1990) reported research indicating that social networks were disrupted by changes and transitions and that individuals actively created and used their networks. I explored whether patients were active agents in constructing and using supportive relationships by analysing their descriptions of their interactions with network members as follows.

Positive behaviour changes in network members

I noted patients' reports of and reactions to positive (supportive) behaviour changes among their network members. I linked the types of positive behaviour change with the type of relationship to see whether certain types of support were more typical of some relationships than others. I noted whom patients described as their main support sources and whether these support sources changed during the illness.

Negative behaviour changes among network members

I analysed patients' reports of and reactions to negative behaviour (stressful) changes among network members and sources of these negative changes. I also explored possible reasons for these changes.

Unchanged behaviour among network members

I noted instances where patients described network members' behaviour as unchanged and possible reasons for this.

Sources of support

I noted any changes in sources of support since diagnosis.

New sources of support-From the interviews and network diagrams I noted from where and how patients had found new sources of support since diagnosis.

Reactivated relationships-I identified whether patients had reactivated any dormant relationships.

Loss of relationships-I noted patients' reports of lost relationships among their network members and whether these losses seemed to be associated with the illness.

5d In what ways did formal and informal support assist patients in coping with illness?

What roles did formal and informal support play in enabling patients to cope with illness? Were different types of support from different sources necessary for effective coping? I examined my data on patients' problems and anxieties and noted alongside, anxieties/problems, the kinds of formal and informal support patients said they had received. I compared and contrasted support from formal and informal sources noting any overlaps.

5e Changes in support patterns in the course of the illness experience

It seemed likely that patients would have different support needs and expectations at different stages of their illness and that network members would respond to them differently at these times. Samples in the Initial Survey, main Macmillan Study and follow-up interviews included patients at various stages of their illness and I re-examined my data for evidence of changing support patterns. I noted changes in types and amounts of formal and informal support during the illness and identified those stages when patients reported formal and informal support to be most helpful.

6 Key issues and theories; identifying core categories

Analysis of qualitative data usually proceeds from a concrete to a more theoretical level. In grounded theory, data are collected and coded at the first stage of analysis. At the second level, relationships between themes are noted and at the third stage, the key issues and theories are noted. The aim of my analysis was to find core categories which described the nature of social support. Strauss (1987) noted;

The generation of theory occurs around a core category (and sometimes more). Since a core category accounts for most of the variation in a pattern of behaviour and its different kinds of appearances under different conditions, the core category has several important functions for grounded theory. It is relevant and works. Most other categories and their properties are related to it. In addition, ... it has the prime function of integrating the theory and rendering it dense and saturated as the relationships are discovered. These functions then lead to

I re-examined patients' statements about problems and anxieties experienced during their illness, to identify underlying core categories. To identify linking themes, I then analysed patients' statements on social support received in relation to these problems/anxieties.

6a Use of discourse analysis

The hypothesis that social support maintained and changed peoples' identities came to me as a sudden insight during analysis of patients' statements about their illness experience.

Having identified the core category, the essence of social support, I proceeded to the third level of analysis. I checked this interpretation against the data from my interviews and the social support literature, using discourse analysis to support my hypothesis. In analysing my interviews with patients, I was looking for statements which described aspects of their identities, whether these were perceived to be threatened and in what ways social support was perceived as maintaining aspects of identity. Discourse analysis was particularly suited to studying identity as a process dependent for its maintenance and change upon social support rather than a fixed intra-personal structure. I looked for statements indicating when patients were talking about their identities. I then searched for statements which indicated if and how positive behaviour (social support) from network members maintained or changed identities. Statements from patients were first categorised on the basis of which aspects of identity were described, e.g. sexual identity. I then categorised statements about network members' positive behaviour (social support) towards the patient on the basis of function (i.e. what is being done?) and form (i.e. how is it being done?). Detailed analysis of patients' statements provided the basis for testing my hypothesis that social support maintained and changed identities.

Having analysed patients' statements in the main Macmillan Study, I looked for supplementary evidence in the Initial Survey. I also tested my interpretation against literature on social support to see if an underlying theme of support as developing, maintaining and transforming identity could be discovered. Writing about discourse comprehension, Dijk and Kintsch (1983) noted that the understander had three kinds of data-information from events themselves, contexts and cognitive

presuppositions. They maintained that third level analysis, that is interpretations, could be constructed first and then checked out with data rather than vice versa, the aim being to reach the best possible understanding of the situation. Dijk and Kintsch argued;

There is no fixed order, at each point, between input data and their interpretations. Interpretations may be constructed and only later matched with input data. We see that persons have the ability to flexibly make use of various kinds of information and that information may be processed in several possible orders, that the information that is interpreted can be incomplete and that the overall goal of the process is to be as effective as possible in the construction of the mental representation. p. 6

6b Checking that the core categories account for most of the variation in behaviour

Using discourse analysis, I had tested my research hypothesis that social support from others can maintain and change individuals' social identities. I now tested the opposite hypothesis that negative behaviour from significant others can threaten individuals' social identities. I searched for patients' statements indicating if and how negative behaviour/attitudes from their network members had threatened or undermined them. I also looked for possible motivations behind negative behaviour as perceived by the patients.

Detailed analysis of patients' perceptions of social support and social identity provide the basis for the analysis of the concept of social support that follows.

Chapter Three

Illness and Social Identity

1 The construction and maintenance of social identity

Combs and Snygg (1959) noted that the greater portion of identity is developed and maintained through interaction with others. Everyday interactions among family members have profound effects upon development of the self.

Human personality is primarily a product of social interaction. We learn the most significant and fundamental facts about ourselves from what Sullivan called 'reflected appraisals', inferences about ourselves made as a consequence of the ways we perceive others behaving towards us. p. 134

Of a number of social identities, a few can be described as core identities because they form the basis of the individual's perceived self, being those perceptions about the self which seem most important to the individual. The self concept is;

the very essence of me whose loss is regarded as personal destruction. p. 127

Examples of core identities are body image and sexual identity. The self concept develops throughout childhood and adult life. It is influenced by bodily structures, especially if society has expectations about them.

From the moment of his birth, our society begins to impress upon the child the fact of his maleness or femaleness (sic) what is expected of boys and girls or men and women in our culture. p. 76

Significant others such as an individual's partner, mother, sister, daughter are likely to be included in his/her self concept. Their attitudes and behaviour are important to his/her self esteem and security. Many authors have noted that loss of significant others can cause morbidity. Research dealing with events that disrupt attachments, such as residential changes and divorce, indicates that loss of attachments is accompanied by psychological distress. It suggests that attachment support imparts an abiding sense of security and well being. When significant others are lost through separation or death, the individual feels that he has lost part of himself.

The phenomenal self may include by identification, persons and objects entirely outside our physical selves. The phenomenal self includes not only a person's physical self but everything he perceives as 'me' at that instant. p. 139

The self concept might include such factors as nationality and religious beliefs. Individuals have a concept of themselves as sick or healthy. Identity may also include ideas about the permanence or immortality of self. Combs and Snygg (1959) defined the basic human need as a need for adequacy and noted that individuals seek to maintain and enhance their identities or 'phenomenal selves'.

It is the phenomenal self, or the perceived self which each human being is forever seeking to maintain. Man seeks both to maintain and enhance his perceived self. p. 44

2 Effects of illness on social identities

Research has shown that it is sometimes difficult for people to maintain adequate self concepts when undergoing changes such as illness which can spoil aspects of their established identities. The degree to which a change or crisis affects the individual's core identity varies from person to person. Combs and Snygg (1959) noted that;

The degree of threat experienced by the person will be in part a function of the peculiar importance of the particular aspect of self under fire at any moment. The more important the aspect of self to the individual, the greater will be the experience of threat. p. 176

Whether having breast cancer is such a significant threat to an individual's identity depends on whether core aspects of the self concept are threatened. Quint (1963) identified three basic changes in the lives of 21 women adapting to mastectomy; the shock of adjusting, a change in bodily appearance and a fear of the future. Change in identity in one area can affect identities in others. Having a mastectomy can affect a person's identity as a woman, girlfriend or wife. Breast cancer presents a double threat, to body image and to wellness. Diagnosis of serious illness often lowers self esteem and confidence, especially with cancer which is perceived as having a social stigma.

2a Permanence or Uncertainty/Insecurity?

Being in control of one's life is an important aspect of identity. For this, predictability is necessary. My respondents faced an uncertain future. Because a

cure of breast cancer could not be guaranteed, most worried about the possibility of recurrence. Anxiety generally decreased once treatment started but many women felt they had no control over their future health and that cancer could return as unexpectedly as it had first appeared.

The worry is as long as it does get cured and it doesn't spread anywhere. That's what worries me you know. They do all these tests and you wonder if it's going to spread anywhere else. PY

CG had been diagnosed with breast cancer and then developed jaundice which her doctor said might be due to malignancy.

It's a terrible feeling. You are going into the unknown. The doctor says I have jaundice. He says it may be gall stones or it might be a growth. It was a shock I felt frightened. I came home and I thought 'You don't look ill.'

Anxiety about recurrence made women suspicious of any aches and pains they experienced. JL commented;

I had a swelling under there (axilla). and I thought, 'God, I've got another lump here.' It was just a reaction to the acrylic jumper I had on. Then lately I've been thinking, 'God, I hope it doesn't come back.'

JC had an inoperable tumour treated with intensive chemotherapy. She felt vulnerable to recurrence.

We know it's away at the moment but there's very few people who don't know there isn't a cure. No matter how good they are it can always come back in different parts of your body. I'm just hoping it doesn't.

EM's cancer had affected her cheerful identity, making her depressed.

I said to Mr K (surgeon) 'I can't seem to get past, 'What if it comes again?' I don't seem to be able to get it out of my mind. That's what makes me have those moments when I'm not my usual cheerful self.'

SL suddenly felt that her future was very uncertain.

I know when the news was given to me back in January, I thought I would never see the end of the tunnel. It was all so dark. I was so depressed. I kept thinking about the future.

EW found coping with the uncertainties of her illness difficult. She formerly took good health for granted. Six women met patients who had developed recurrence many years after their initial diagnoses, emphasising the uncertain future. JJ met a woman who had developed recurrence 15 years after her first mastectomy.

It's sad to be clear for 15 years but that's life isn't it. If we all knew what was in front of us. we'd all want to go tomorrow. There's going to be good things in front of me. I'm going to get over all this.

Sometimes DW felt overcome by what had happened to her.

I can forget it for hours on end. I think the worst time is when I wake up in the morning and I think, 'What is it?' Then it all rushes over you. Sometimes you can hardly believe it's happened to you.

After JH's first mastectomy 16 years previously, her recovery had seemed more assured. Following her second mastectomy she had to take the drug Tamoxifen.

It's the fact that I'm having to take it (Tamoxifen) for life. It's like a constant reminder you know. After the first mastectomy I thought 'I'll get my prosthesis, I'll get back to work and I'll get on with my life.' Taking that I think, 'Oh, where's it going to come next?' The way I kept my sanity the last time was that they said the knife was the surest way. I had that operation but I'd got peace of mind. To begin with when I got the Tamoxifen I thought, 'They are expecting this to crop up somewhere else.'

MH's parents had both died of cancer.

I think it's the unknown that's frightening isn't it? When my father was dying of cancer I don't think he knew he had cancer.

MH's husband remembered her first reaction to the diagnosis.

I remember M coming in through that door and saying, 'My mum died of it, my dad died of it and now it's going to get me.' That was a dodgy time because I think she had set her heart on it not being malignant.

Some women had inoperable breast cancer and despite having other therapies were left with a feeling of treatment being incomplete. EC was uncertain of the effectiveness of radiotherapy and chemotherapy.

They used to measure it (tumour) every Monday but they don't measure it now. I think 'Has it gone?' 'Why are they not still measuring it? How do they know what's going on inside?' I did get a bit better but now it's gone away off again (inflamed breast). I imagined it was everything going again inside. I'm always conscious of it but you can't do anything about it.

AC's inoperable tumour had been treated with radiotherapy and hormone therapy.

The only thing that bothers me about the Zoladex injection is that it's very hit and miss. You just turn up and hope someone will give it to you. Many a time I was in tears when I was waiting. I felt totally abandoned. I got to the point where I thought, 'Right I'll contact Cope (self help group). I'll find out, "Am I normal to feel like this?"'

At her last clinic appointment, AC was told that there were 'no cancer cells'. After eighteen months treatment she was 'beginning to get depressed'. She feels 'a different person now'.

AF and CB (with advanced breast cancer) worried how long their disease could be controlled medically.

How long can you go on with not knowing? Mind you part of me doesn't want to know. You don't know what's happening. It's like being in limbo. It's been like that for two years. When you think you've got over one bit of it, something else crops up. AF

Ideas about personal immortality begin in early childhood. Young children are often unable to understand the permanence of death, thinking a relative who has died will return. Teenagers and young adults tend to see themselves as relatively indestructible with an unlimited future. Many apparently healthy middle aged people have an expectation of living to an old age. Religion reinforces ideas of the immortality of one aspect of the self, the soul. According to Neuburger (1987) all the major faiths contain some ideas of an afterlife. whether it be reincarnation (Hinduism), rebirth (Buddhism) or survival of the soul in the presence of God (Judaism, Islam and Christianity).

Many of my respondents had not previously thought much about their death. Now, because of cancer's association with death, they were stopped in their tracks. It was a threat to the very core of their self. HM's mother had died of breast cancer, her cousin had had a breast cancer recurrence. This increased HM's worries about her own prognosis.

You've got to die of something in the end. My mother died of lung cancer. She had secondaries before they discovered it (from the breast). I'm not planning on doing that just now! I've got far too many responsibilities. I'm far too busy. Someone has to keep this place going you know!

Since her youth, SS had feared dying of cancer and confronted her fears by remembering she was only 46 - strong enough to fight the disease.

I suppose when I was younger, I thought, 'What if I die of cancer?' That's everybody's fear, to die of cancer. I never thought at 46, I would have cancer. Folk will say to you, 'You'll get on all right. You are strong enough. You're okay.'

RA (health visitor) reported that AH was struggling and worrying about her future since her breast cancer diagnosis.

Her first reaction was, 'I'm going to die. People die of breast cancer. It isn't a local disease, It's a systemic disease.' I think that was the predominant thing and she couldn't get beyond that point. She had a lot of knowledge.

DL (health visitor) felt SL had been brought face to face with her own mortality.

She's 55. You are just beginning to realise that you are not immortal. Suddenly it's brought home to you. Is it going to be downhill from now on?

EA felt that she needed to face up to her mortality before she could move on.

I did go through a week like that, thinking negatively, but you have to go forward. Some people suppress their thoughts. Some people suffer from depression because they can't express themselves.

2ai Threat to life philosophies

Lynam (1990) found that cancer was seen as a threat to her respondents' lives as they were accustomed to living them and they embarked on an examination of their life philosophies. This examination helped them find meaning in their experiences and to perceive the experience of living with cancer as manageable. Kelly (1991) called this examination, the intersubjective level of coping. It involved people with stomas making sense of what had happened, explaining and justifying what they were doing now and would do in future. Gyllenskold (1982) found that over half her 78 breast cancer subjects reported a life reappraisal due to the cancer experience. Quint (1963) found that some of the 21 women adapting to mastectomy in her study described a new attitude to life and a reordering of priorities with an emphasis on relationships. For some of my respondents, the way they used their time was highlighted by the illness. They resolved to spend more time with their families. The importance of certain relationships was also highlighted.

2b Sick or healthy person?

People confronted with a crisis such as illness tend to become disoriented. They are uncertain of both outcome and future. The diagnosis of breast cancer may cause longstanding emotional changes to the concept of self as a well woman. Many now regard health more positively than mere absence of disease. Woods *et al.* (1988) asked a sample of 528 American women, 'What does being healthy mean to you?' Cited health images included;

absence of disease	56.5%
positive feelings	49.2%
fitness	43.8%
practising healthy life ways	23.9%
harmony	23.6%
role performance	17.9%
adjustment to environment	13.6%
positive body image	13.8%

88% of images fitted an 'exuberant well-being' model of health. Older women had fewer images complying with this model than younger women.

All this is borne out in my research. Women spoke of cancer threatening health and even life. They felt they could no longer trust their bodies which had, in a way, betrayed them. Many of them had shown no signs of ill health before the cancer diagnosis. This added to their fear since cancer could suddenly appear without warning. JB who now had recurrence of her breast cancer spoke of feeling unexpectedly vulnerable after her mastectomy four years previously.

When I was having the mastectomy, immediately afterwards was a difficult time. I felt it had changed me quite a lot, not just because my breast had been removed. I didn't think I'd ever be quite as active again or as able to cope with things. Up to then I'd never really been ill. I felt it had done quite a bit to me, physically, and I was not quite the same person. After I'd had the mastectomy I really did feel ill, if not ill at least physically less able to do things than I had been. The mastectomy was a reminder, you couldn't forget it to the same extent. I felt very vulnerable at first going out and doing things.

2bi *Being labelled sick*

According to Becker (1963), labels can have powerful effects on attitudes and behaviour. A label is not neutral. It evaluates the person concerned. It can have master status in that it colours all other statuses possessed by an individual, for example, status as mother, friend, work colleague. Others sometimes see and respond to the individual in terms of negative characteristics associated with labels.

deviance is not a quality of the act a person commits but rather a consequence of the application by others of rules and sanctions to an "offender". The deviant is the one to whom the label has been successfully applied, deviant behaviour is behaviour that people so label. p. 91

Self concept is largely derived from the responses of others. People tend to see themselves in terms of labels-a self fulfilling prophecy. Discussing counselling,

Brearley (1993) noted two extreme approaches in the way clients related to problems. One approach identified with the problem which became the entire focus for the person's sense of identity through a process of self-labelling. Another was for clients to regard the problem as an enemy to overcome. In the first case it was necessary to become separate from the problem in alliance with the worker, while in the second case the person had to own a bit of the problem.

I considered the implications of Becker's labelling theory for women with breast cancer. People not only receive medical diagnoses but also become aware of society's expectations regarding different diseases and tend to respond psychologically to the labels. Why do some diseases attract such negative labels for their sufferers while others do not? Labelling tends to be selective; chronic conditions such as epilepsy or asthma are more likely to be perceived as prime statuses than are acute conditions such as appendicitis. This is probably because chronic diseases can only be controlled, not cured. In a study of diabetic patients, Nyhlin (1990), found that diabetic status coloured other statuses in the eyes of health care workers.

For some respondents, it seemed to be very important to get the feeling of being acknowledged as a 'whole person' by the health care personnel. Frustration and anger were experienced because of failed expectations, a matter that respondents also had to come to terms with. p. III; 9

Diseases like cancer which are feared because of their association with suffering, loss of physical attractiveness and poor prognosis attract negative labels. A Cancer Relief Macmillan Fund Survey (1988) of public attitudes to cancer in the UK showed that it was still the most feared disease, although AIDS was rapidly attaining a similar status. At what point in their illness history, if ever, do individuals with breast cancer cease to be regarded predominantly in terms of their disease and become 'whole people' again? Monitored over many years for signs of recurrence of their disease, do people definitively cease to be patients and become 'well'?

In my research, five women had their breast cancer diagnosed at screening and had been unaware of any symptoms of the disease;

It was completely out of the blue. When I went for screening, I got the mammogram. Then the consultant came to do a scan. I said, 'Is there something suspect here?' He said, 'We're not very sure.' He said, 'We'd like you to go to the Longmore.' As soon as I heard that I thought, 'Oh my God.' My friend had been in there. They told me I had a cancerous tumour. It was a terrible shock. JM

EC's lump was also discovered at screening. She found herself wishing she had not attended.

It was about ten days later that I got the letter. Immediately I had a wee feel around and I found it. I can't say I'm someone that checks, just very occasionally. I would say that was quite a shock. I couldn't see any positive bits to it. You sometimes wish you had never gone up.

SL suddenly found herself labelled as a patient with cancer, although she had felt quite well before screening.

There was nothing wrong with me. I was working alright and suddenly somebody tells you you've got cancer. You feel awful. I don't know if I will ever forget the feeling that I had cancer.

2bii Labelling oneself as sick

Thirty respondents discovered their own breast lumps and had more time to adjust to the possibility of having cancer than those diagnosed by mammography. They still reacted defensively.

Five women suspected that they had breast cancer ahead of the diagnosis.

I found it in the bath on the Saturday night, just down there at the breast bone. I couldn't discuss anything with anybody because I didn't know whether it was cancer or not until I got the scan. We were all hoping it was going to be a wee abscess or a cyst, but at the back of my mind, I had an idea it wasn't. I think that was the most worrying time of the lot. JC

JN delayed reporting her breast lump for three weeks but suspected that it was cancer.

The doctor said, 'All these lumps aren't malignant' but at the back of my mind I thought, 'It must be.'

MW's mother had had breast cancer and she was convinced that she now had it too.

I knew before I went what it was. I went to the doctor and said, 'It's a cancerous lump.' She said, 'How can you be so positive?' I said, 'I know.'

MC found it strange.

One month you feel OK and then to be told you have a tumour.

2biii Defending a healthy identity

Thirteen women delayed reporting their breast lumps. The cause of the delay seemed to be a reluctance to accept that they might be sick and more specifically, that they might have cancer. Over half the women defended their identities as 'well women' by some or all of the following strategies;

delaying reporting symptoms,
denying the implications of symptoms,
distancing from symptoms
normalising symptoms.

In a Swedish study of women with breast cancer, Gyllenskold (1978) found that most women used 'shock' or 'panic' to describe their feelings on discovering a breast lump. Of the 21 women in that study, 10 contacted a doctor after a delay of between two and over six months. Gyllenskold noted that people can describe what cancer symptoms are like, without appearing to understand that their own symptoms indicate cancer.

What stops them are defence mechanisms involving denial, suppression or rationalisation. Cancer is linked with such threatening and frightening notions, that the defence begins to operate at once, unintentionally. p. 44

2biv Delaying reporting symptoms

MP tried to convince herself she did not have breast cancer symptoms and delayed telling her daughter. Having nursed her husband, she felt this had conferred some kind of immunity on her.

I should have gone to see about it. Maybe in my case I was thinking, 'Well I've been through a terrible time and nothing would ever be as bad. Surely nothing would happen to me after that.'

HC delayed reporting her suspicions about her retracted nipple, but her anxiety about it affected her health.

I noticed the nipple was going in and it was going in pretty deep. My breast felt awfully hard and I felt there was something there. I had my suspicions about it. The doctor said, 'It's because you've been anxious, that's put your blood pressure up.'

Denial is a common defence against threats to identity. It can be helpful in short term coping with illness. It is dysfunctional that a woman delays reporting symptoms. Lorde (1980) described feeling disbelief after her breast cancer diagnosis.

All the time as a background of pain and terror and disbelief, a thin high voice was screaming that none of this was true, it was all a bad dream that would go away if I became totally inert. p. 30

Eight women denied their symptoms of breast cancer initially, saying that these signs of abnormality were not part of their identities. JL found her own breast lump.

My daughter's dog came in and she just jumped up on me and the pain was terrible. For about two weeks I was in agony with it. Then my breast all suddenly changed shape. So eventually I went to the doctor. I said, 'Please doctor, say there's nothing wrong with me.' He says, 'You know yourself there's something there don't you?' So I was sent to hospital. I fought it the whole of the way.

Mary M's first reaction to her diagnosis at screening was denial.

I kept saying, 'It's a mistake. I don't feel anything.' How can you have something that they say is dreaded? It's awfully hard to fathom it out and you associate the word cancer with somebody in terrible pain.

After finding her lump, JN denied the possibility of breast cancer.

I found it myself. I didn't want to think about it at the time. It took me about three weeks before I realised I had to do something about it.

AD had had mastitis when breast feeding her daughter and dismissed the thought of the lump being anything more serious.

When I'd been breast feeding M, I had mastitis and it was very sore, but I didn't do anything about it immediately. When I went to the doctor he said, 'Oh if you had come right away, you'd have saved yourself a lot of suffering.' My Mum came with me to the (breast cancer) staging meeting. I didn't really want my husband to come because my reasoning was, 'They can't give me bad news with him not there.'

JH's breast cancer was diagnosed at screening but prior to that she had had breast tenderness which she did not report.

It wasn't a lump as such but it was very tender. Every time I took my bra off I was in agony. I was going to the doctor but I thought, 'I've got an appointment when I come back, I'll just leave it.' I always thought anything connected with cancer wasn't painful.

BI had not allowed herself to think that her lump might be malignant.

I found the lump myself. I kept feeling it and thinking, 'It's gone away. No, it's still there.' It was difficult to decide if it was a lump or whether it was my rib. The doctor said, 'You will want to know whether this is malignant or not.' The word hadn't entered my head. I hadn't allowed it to. I'd been keeping myself going by repeating what my daughter had said, 'Don't worry about it.'

2bvi Distancing from symptoms

Two women distanced themselves from the threat of a cancer diagnosis. SR was unable to make any decisions about her treatment until urged to do so by her sister.

I went to the clinic on the Wednesday and got the bad news. It was a shock. All that day you were in a wee world of your own. It was like living in limbo for a few days.

EC felt that she wasn't present as the doctor told her the diagnosis.

I came back in half an hour and the doctor said it was malignant. I mean he was telling someone else it was malignant. I wasn't there. He said, 'Are you all right?' I said, 'Yes, I'm fine.' I was up in the air somewhere, you know. It's unreal when someone tells you that. I suppose it's a sort of safety valve.

2bvii Normalising symptoms

Another defence mechanism was to regard possible breast cancer symptoms as normal body changes. Three patients attributed breast symptoms to their menstrual cycles.

I thought, 'Maybe it's the time of the month.' I left it for a wee while, but then I went back again and told my daughter who said I had better go and see about it. EL

I started feeling sore and I thought 'Oh my goodness it's really heavy and sore.' I always have soreness before my periods, then it would pass over. I thought, 'It's happening too often, let's go and see.' SS

I discovered the lump myself. I thought, 'Oh it's just period time, it's just a bit lumpy.' Then it started to grow. MB

AC thought her symptoms might be connected to the menopause.

Part of the worry was, 'Am I making a fuss about nothing? Is this something connected with my periods?' My periods stopped in June. One worry was, 'Is it a tumour?'

MP normally had lumpy breasts.

It was just a wee dent underneath. I always kept a check on it but I thought that for breast cancer, it was lumps. Well, we are lumpy anyway aren't we? I never thought much about it but it was in my mind. As time went on, it began to nag.

DW thought a breast lump was just a sign of old age.

I found the lump on one side myself but convinced myself it was nothing you know. It was a while before I went.

MC attributed wrinkling of the skin on her breast to ageing.

For a wee while I had felt as if that breast was getting a bit big for my bra and I kept pushing it back in again. Then I noticed it was kind of wrinkly but I just thought, 'Och, I'm getting older.' Then I just happened to put my hand on it and I thought, 'That feels hard.' I said to Bob (husband), 'You touch there for me.' He says, 'It's a wee bit hard Margaret.'

Neither LB nor her GP thought a breast lump was malignant due to her youth and good health.

I haven't felt physically ill. It's more emotional, the strain of it all. There's the shock. Your whole life is turned upside down.

SR did not have any symptoms which she associated with illness.

I think maybe if you had been ill, or maybe lost a bit of weight, you would have thought, 'I'm not feeling right.' With not having symptoms there was no reason to think there was something really wrong with you.

2c Dependence or autonomy?

Most of my respondents had previously considered themselves competent, independent people. Now their disease made them feel uncertain of their physical and psychological coping abilities and sometimes caused them to question whether they could ever return to normal life. Lynam's (1990) research into the support of young adults with lymphoma and sarcoma emphasised the importance to identity of their ability to fulfil social roles. All her respondents defined who they were in terms of their social roles and relationships and the feelings derived from them. Cancer's impact was seen in how it influenced their abilities to fulfil social roles or changed social relationships. My respondents also worried about their competence to carry out their normal social and work roles. Many found themselves temporarily unable, a few permanently unable to cope.

2ci *Physical dependence in illness*

Breast cancer and its treatment imposed physical limitations which sometimes surprised patients. These were usually temporary and were cast aside on the road to recovery. However, in two patients with advanced disease, physical dependence increased as the disease progressed. Physical limitations meant that women were unable to carry out their normal social and work roles, with implications for self esteem. Oakley (1974) drew attention to how female identities could be moulded around the housewife image;

Preparation for housewifery is intermingled with socialisation for the feminine gender role in the wider sense. p. 113

Women in employment have still found their roles as homemakers to be an important part of their identities. Clark and Haldane (1990) found that

... housework and cooking are also 'moral' categories which 'say something' about a woman's feeling for her husband and their marriage and which communicate to significant others such as parents, siblings and friends. p. 27

Most of my respondents were unable to carry out their normal household and family tasks in the period after surgery or during other forms of treatment such as chemotherapy or radiotherapy.

2cii *Temporary dependence*

AB worried about being unable to fulfil her normal role at home after her mastectomy.

I'm uncertain of what sort of a state I'll be in when I get back from hospital. Am I going to require any special help? Am I going to be a nuisance? Am I going to be able to look after myself?

Following her discharge home, her sister reported that AB was 'exhausted ' by too much housework, despite her husband taking time off work to help. EH was a home help and had lead an extremely busy life prior to her diagnosis. Now she hardly recognised her former self.

I worked 9 to 1 at the office. I never used to have a weekend off. Then I had Michael (grandson) Monday, Tuesday and Thursday afternoons. Then I found this lump. I think your body tells you 'Slow down'. When I was working I had to get things done but now I'm not, I think, 'Och, tomorrow will do." I just seem to have slowed down an awful lot. I thought it would only take about a month and I'd be fighting fit. I didn't realise I was going to feel so useless. I wonder now how I did what I did.

CN had had bilateral mastectomies and was surprised at how tired and old she felt.

The tiredness surprises me. I was one of those lucky people, you know. I had loads of energy. I could cope with my job (bus driver), my housework and everything without feeling tired. Now by the time I've washed and dressed in the morning and sat down, I can feel my eyes getting heavy. You think, 'Gosh I feel like somebody of ninety.'

IH lacked the energy or motivation to do things. Formerly a keen gardener, she had not been into the garden for several months. She worried about how her illness would end. SL was off work for several weeks following discharge from hospital. She was anxious and unable to do much housework. She felt she had changed from being fit to being a sick person.

I am very nervous if my house is not done properly. I was very sore, particularly my right arm. Naturally, my husband has to work.

She also worried about how she would cope with returning to full time work.

I wish I could have part time work say for a few months and then gradually go back to full time. It's a very stressful job. You bring work home. It's a responsible job, particularly when you are in charge.

2ciii Permanent dependence

Sometimes illness produced more permanent dependence. JC had to give up her part time work which she enjoyed when having intensive chemotherapy. She resumed her identity as a disabled person on the advice of her GP.

I liked work. I worked in a fish shop. Three days a week I worked. After I took the lump, my doctor said, 'Just go back on the disability.' (for arthritis).

CB with advanced breast cancer, had prided herself on taking little time off work. Now she had to take time off for hospital. Her disease and treatment made her feel tired. However, her work was an important to her identity. She wanted to continue full time for as long as possible.

There are a lot of girls in the work who take one day here and two days there. I'm not that sort of person. Before all this happened I was never off you know. I find that if I'm working I feel that much better. I think it gives you a purpose. It takes your mind off the problems. I do feel I need to work, you know.

AF (with advanced cancer) was unsure of her ability to cope with work.

Being in here (home) and not being able to do anything, it's driving me mad. I don't know if I could cope with work. I think fear is a big part of it.

AF later had a course of chemotherapy but this made her feel tired and old. Her illness and its treatment had undermined her self esteem.

It's (chemotherapy) working but I keep asking myself, 'Is it worth it, to be like someone in their dotage?' It took me an hour last night to wash up dishes. I'm going in to work today. God knows how I'm going to do it. I'll have to try. I shouldn't be feeling like this (sick). There's so many things I want to do and I just can't do them. You can't help doubting yourself.

2civ Concealing dependence

Treatment left MW feeling exhausted. However, her health visitor (CR) noted that she was trying to do more than she could.

She wants to do more than she's able to and she had stood and ironed for half an hour and she'd been absolutely puggled after it. She goes to the shop at the corner. She had to get someone to bring her back under the pretext of, 'Would she like a coffee!'

MW felt a need to conceal her inability to cope from her family.

2cv Testing competence

Sometimes women worried about whether they would ever regain their former physical independence. DW was an elderly widow with bilateral mastectomies. She worried about coping with housework and tested her competence.

To begin with there was quite a lot of pain. When I came out of hospital I said to my cousin who was making the bed, 'Do you think I'll ever be able to do that?' Up till Friday I hadn't done shopping. I thought, 'One thing I've never done is open my garage on my own.' It's quite high but I managed to do that and get my trolley out and go shopping. I felt a bit tired after that but I was pleased I was able to do it.

SR wondered how she would cope with working again full time.

2cvi Relearning skills

Some women had the added pressure of having to learn new skills on returning to work. AH commented;

The social work department is in chaos at the moment. The next round of jobs is coming up which I need to be applying for. So I need to get back in touch and be in there. My job is going to disappear completely. It's a very traumatic time.

SS felt she would have to relearn aspects of her job which had changed while she had been ill.

It's like going back to the beginning again because I've been off six months. They've done a lot of new stuff (cake decoration) and I've not done the new stuff so I've got to learn. They've been doing lots on tops of cakes and doing sugar paste animals. There's new designs of wedding cakes.

2cvii Regaining independence

For some women, the desire to prove that they could cope manifested itself in resuming normal family and work roles as soon as possible. JM was a catering manageress and longed to put the constraints of her illness behind her.

I'm just dying to get on with my life. I just want to put it behind me of course. I thought the treatment was never ending.

HM made a conscious effort to move out of the sick role and return to work.

There comes a point where it doesn't really do any good to sit at home. You need to switch yourself up a gear I think. ... or you can wander round feeling sorry for yourself for ages. I think it's good to get back to feeling reasonably normal.

EM felt unwilling to accept the dependence her illness caused.

I'm still feeling tired. I try not to worry about it. I think, 'Maybe this is normal.' I thought, 'Once I'm all healed up I won't feel tired.' Then I thought, 'When I've got my permanent prosthesis, I'm bound to feel full of life. That's me back to normal, ready for tackling the decorating that has to be done.' I can't even move the table from there to there. Maybe it's that I'm not ready to slow down.

2cviii Finding new kinds of independence

AC was made redundant. After her initial disappointment, she realised she could achieve another form of independence by being at home and spending her time as she pleased. She also joined her local breast cancer support group where she hoped to help other people.

I hadn't realised how exhausted I was and I must admit I quite enjoy being at home. The first four weeks I was very, very tired and I had no energy but since then I've done decorating here and for my friends down the road. I've helped a friend in Durham. It's just been all go and I've thoroughly enjoyed it.

2cix Psychological dependence

People's ability to perceive themselves as capable and independent may be temporarily or permanently impaired by illness. Erikson (1965) maintained that gaining autonomy is an important part of development of the self.

If denied the gradual and well guided experience of the autonomy of free choice (or if indeed weakened by an initial loss of trust) the child will turn against himself all his urge to discriminate and to manipulate. p. 244

Johnson (1991) found that the process of regaining control after a heart attack involved three dimensions; an ability to predict outcomes, make informed decisions and act on decisions. Heart attack victims had a sense of uncertainty which diminished predictability. They also lacked understanding of their bodies, undermining their sense of power and control. No longer able to trust their abilities and relying on others' support, undermined their independence.

2cx Loss of control over health

Psychological dependence arose when my respondents felt unable to control the effects of disease. They lacked control over its course and possible recurrence, treatment, their changed physical appearance and feelings of tiredness and anxiety. Given breast cancer causes are presently unknown, they were uncertain how to prevent recurrence. Their lowered self esteem sometimes made them unable to trust their abilities. To regain control over their bodies and lives my respondents needed some predictability about the future, information about their disease and its treatment and involvement in treatment decisions. In her autobiography, Lorde (1980) was afraid of not being in control of her body after her breast cancer diagnosis.

I was also afraid that I was not really in control, that it might already be too late to halt the spread of cancer. ... The year before as I waited almost four weeks for my first biopsy, I had grown angry at my right breast. I felt as if it had already become separate from me and turned against me by creating this tumour which might be malignant. My beloved breast had suddenly departed from the rules we had agreed upon to function all these years. p. 33

Knowing what caused her cancer would have given my respondent, LB a sense of control over the disease. Not knowing made it difficult for her to adopt a logical, positive approach.

You've just got to try and fight it logically and positively. We eat quite sensibly but it really makes you think. You wonder why it has happened. They really

don't know just now. I'm sure the pill (contraceptive) I was on was a low dose of oestrogen. It's only now you start reading the notes. There's a part that says some studies suggest a possible link with breast cancer.

Feelings of loss of bodily control were partially counteracted by regular medical checks. SS worried that her cancer might have spread despite tests showing it had not.

I don't know whether I've really got to grips with it yet. I mean it's at the back of your mind, 'Is it all over yourself? Is it all over your body?' I suppose the tests have showed that it's not.

PY again suffered a severe skin reaction following radiotherapy, as with a previous cancer. This made her feel very apprehensive about the future as she wondered whether her skin would ever heal.

The main problem is trying to cope with the reaction from the radium. It makes me feel so miserable and so depressed.

JL sometimes had nausea and vomiting and began to be afraid of leaving her house in case she was sick.

I'm getting that I'm frightened to leave the house, because, when I go to the shops I'm sick. I'm frightened of public transport in case I'm sick. I can't go on like this.

JC's intensive chemotherapy gave her nausea and vomiting.

I've not been able to go out. I've had that kind of nausea all the time. You were always frightened that if you went anywhere very far you were going to be sick. I'd hate to be sick outside.

2cxi Loss of confidence in coping abilities

EC, a psychiatric nurse, felt very helpless when her breast cancer was first diagnosed.

I just don't think I've got it in me to cope with it somehow. It's sad but it's there. I suppose you just go through it a step at a time and you somehow get through it. I tend to be ahead of myself. I somehow plan the next six moves which is not really very good.

AH had successfully suppressed her feelings of vulnerability only to find them surfacing after the busy Christmas period.

I was very down at that time. I think it was all sorts of things but I think it was mainly around that I'd been very active and very positive, wanting to get back to

being physically okay, determined to do everything. I was putting the mastectomy away somewhere. I suddenly felt very vulnerable physically which I hadn't been doing. It just felt very difficult to deal with all the feelings that had been there a little lower down, pressed down a bit.

SM suffered from excessive anxiety and 'panic attacks', exacerbated by her breast cancer. She had felt secure in hospital but unable to contain her anxiety since discharge.

I go in a mood sometimes. I just feel like running away. I speak to myself and say 'Now just get a hold on yourself.' I sometimes think I'm going doo-lally. It's been a terrible, terrible experience, not just with this but the bereavement, everything. I thought it wasn't coming to an end. Sometimes it (anxiety) comes on that quick it's horrible. It's like I'm choking. You seemed to be fine when you were in hospital. I felt secure.

2d Stigmatised or normal person?

Having cancer can be stigmatising. Having breast cancer can be doubly so because it threatens both sexuality and health. Lorde (1980) felt like an outcast after her breast cancer diagnosis. After discharge from hospital, she found that some people avoided her because their identities were threatened by her cancer.

The label of cancer is often associated with mystery and death. Cancer victims may find that they are not accepted by others in the same way as before diagnosis. Goffman (1968) noted that the central feature of the stigmatised individual's situation was lack of self acceptance and acceptance by others of aspects of his/her social identity.

It is a question of what is often, if vaguely called 'acceptance.' Those who have dealings with him (stigmatised person) fail to accord him the respect and regard which the uncontaminated aspects of his social identity have led them to anticipate extending, and have led him to anticipate receiving; he echoes this denial by finding that some of his own attributes warrant it. p. 19

Anyone with cancer has to face society's attitudes to malignant disease which are extremely fatalistic. The sufferer is reduced in people's minds from being a whole and normal person to being a tainted, discounted one, a stigmatising experience shared by families of patients with cancer.

Cancer had frightening connotations for many of my respondents.

It's a frightening word isn't it? When you're able to say it to yourself, it's better. At first I couldn't think about it. I thought, 'God, It's happening to me.' I think

it's the word cancer. I kept saying, 'It's a mistake. I don't feel anything.' You associate the word cancer with somebody in terrible pain. MM

People won't say that word cancer. People have got visions of you sitting there fading away. EH

Sontag (1979) noted that in the popular imagination cancer equals death. My respondent, SS had had other illnesses but felt that having cancer was much more frightening.

I ask 'Why is it me who has breast cancer?' I mean, I've had illnesses. I've had the goitre done but why should I have cancer? Cancer is the big thing. It was always referred to as the big C. It's just a word but it conjures up all different things in your mind. Cancer, I can't do this. I can't do that. I can't go there.

HM felt that having cancer was more frightening than any of her other ailments.

I've had various operations but it's just the word cancer-it's frightening you know. I kept saying to myself, 'I'm not going to get down about it.' But I couldn't help myself. I was upset with my back when things didn't work out right but when I got the news it was cancer, I went over the road there and I bought a bottle of whisky.

EM looked after her father-in-law for the last six weeks of his life. She saw cancer as the ultimate threat to her identity.

We looked after him at weekends for six weeks. It was really terrible and that was the sort of future we could envisage when the doctor said I had cancer. It frightened you so much just to say the word cancer. That was what you would envisage, pain, and lopping bits off here and there and it's still growing. Nothing could be any worse than hearing you've got cancer. I don't think I've experienced a feeling like that before, how much the world suddenly fell apart just with one word. It conjures up such a lot of pain ... and the end result is usually the same.

Several members of SL's family had died of cancer. She associated it with death.

The minute you hear the word cancer you feel, 'Cancer the killer.' I think it's the wrong conception. I don't know if I will ever forget the feeling that I had cancer.

AF found her advanced breast cancer embarrassing because it was incurable and some people avoided her.

It's an embarrassing disease. At times I feel as if I've got a big sign up saying, 'Beware Cancer'. There are a lot of people who'll not come near you if they know you've got something like that. You feel as if you should be ringing a bell saying 'Unclean' or something. You tend to keep it to yourself. I mean it's not the sort of thing you go spreading around. Other people, you feel are watching you, just waiting on you popping off.

Cancer is a mystery to many people since its causes are unknown, adding to its aura of fatality. IW had had TB and compared attitudes towards the two diseases.

You wonder why some of the cells go roguish. I asked Mr D (surgeon) but he doesn't know what causes breast cancer. In my day it wasn't everyone that admitted that they had TB. It was a kind of disgrace. Perhaps not everybody admitted they had cancer either. I think they do talk about it more now because they are not so ignorant as they were years ago. My friend used to do shopping for me when I had TB. The woman in the shop said, 'Are you not frightened of going into her house in case you get it?' My friend said, 'I'm more frightened of you. I don't know what you've got but I know she's alright.' Ignorance has a lot to do with people's attitudes to cancer.

JB never mentioned 'cancer' during my interview with her but referred to 'something that ought not to be there.'

Cosmetically, at my age it didn't worry me too much to have the breast removed. I felt it was better than having something there that ought not to be there.

MC observed;

I felt, 'Why me?' I was quite a good living person. I breast fed my two girls. The only thing was I was an older mother for the first child. I was 30. I was never on the pill. They say that being an older mother can cause breast cancer. None of our family were bothered in that respect. Breast cancer seems to be that widespread. You often wonder how you got it. It's kind of within this age group - their 50's sort of thing. Perhaps it's something to do with the menopause.

CN, a young Chinese woman, wondered why she had developed cancer and asked, 'Is there a diet for cancer?'

2e Damaged or normal sexuality?

One of the most damaging aspects of breast cancer is its effect on body image and sexuality. Hogan (1980) suggested that sexuality is the quality of being human.

Sexuality encompasses the most intimate feelings and deepest longings of the heart to find meaningful relationships.

Sexuality is linked to self concept which in turn affects self esteem and the ability to relate to others. Sexuality is concerned with how a woman views herself, not just how she is viewed by others. Breast cancer and breast surgery may pose a great threat to the sexuality of some women and some threat to most women. Research (Maguire and Hopwood, 1988) has shown that even if women had good sexual adjustment prior to diagnosis, up to one third develop sexual problems afterwards, including being less interested in lovemaking. Apparently, it is not the extent of

surgery that is the key to women's reaction but the fact that any treatment was necessary. The breast is a symbol of womanhood and one of the symbols of motherhood. For many women, bearing children and caring for them is an important part of their life. Breast cancer is a potential threat to this role. Breasts are also a sexual symbol and may play an important part in a couples' physical relationship. Valanis and Rumpler (1985) maintained that the meaning of breasts to women comprised a complex interaction of cultural and psychological factors.

- a society's view of breasts
- b past learning from parents and interaction with family and friends
- c present experience with family and friends
- d a woman's personal view of her body

There is therefore a need for women to maintain positive sexual identities not just for their husbands/partners but as an integral part of personality.

2ei Effects of surgery on body image and sexuality

All my respondents who had mastectomy (n=16) expressed concerns about their changed body image. The prospect of mastectomy was very threatening to some women. EC had already had a lumpectomy.

The day they told me I was to have it off, I was devastated. I was howling my head off. J (ward sister) comes up and says, 'You'll have to think of a reconstruction.' I said, 'Oh no.'

MW was very upset at the prospect of a mastectomy but realised that saving her life was more important.

I'd asked Mr D (surgeon) straight out on Monday, 'Am I going to lose my breast?' He'd said, 'Quite honestly, 99% yes.' I just went to my GP who is brilliant. I didn't even get my bum on the chair and I broke my heart. I have been very positive from the Monday evening when it all flooded out. Your own self esteem goes. My attitude was, 'I'd rather lose my breast than lose myself.'

SS' worries were typical.

I think it's going to hit me when I go for the operation. It's like losing a part of yourself.

Initially, SM did not want to think about mastectomy and did not discuss it with the other patients.

I went back on the Wednesday for the results and he said it was a tumour. The question I asked straight after that was, 'Will I have to have a mastectomy?' He said, 'There's every possibility.'

After surgery, women were very self conscious of their new shape, thinking that it would be noticed by all. JJ felt that mastectomy threatened her sexual identity.

It's like taking away part of your womanhood. Perhaps I'm only saying that because I'm the age I am now (38).

Two elderly women also expressed anxieties about their post mastectomy body images, showing that these concerns are not limited to the young. DW, aged 70, had had a double mastectomy and avoided looking at herself in the mirror as she disliked her appearance. HC, an elderly widow, had similar feelings.

I was a bit taken aback at first but I mean it's just one of these things. You've just got to accept it.

Although patients having lumpectomy are warned that mastectomy may later be necessary, the news usually comes as a shock to them. MM was very upset at what remained of her breast prior to her readmission to hospital for mastectomy.

It looked a poor wee battered thing. Why should I cry about it? I'm not neurotic or highly strung. I'm a realist but the morning I was going into hospital, I went into the bathroom, took my clothes off and looked at myself, crying my eyes out. 'Mary', my husband said, knocking at the door, 'Come on out of there. What's the matter?' I said, 'I'm not going. I'll definitely die.' He said, 'No, you won't. What's brought this on?' He had an awful job coaxing me out.

AH had presurgical treatment for her large tumour and found it difficult to accept the prospect of mastectomy.

I'd have found it harder to have actually gone straight for surgery. I don't think I've found it easy anyway but I think it does give me some time to come to terms with it and to be able to talk to people.

The process of tissue expansion prior to insertion of the silicone implant was a continual reminder of her lost breast.

I think it's quite hard over this period because it's one of the things that constantly reminds you about it. Also, right now, I'd sort of got used to the way I looked in a way, bumps and all and now it looks worse really. It sort of shows up all the nobbles. It just feels so strained to touch because it's so very hard. Now I look peculiar because it's so high up.

Six months later, she was still unhappy with her reconstruction. She said that her breast was hard, rather high and sometimes slightly uncomfortable. It proved

difficult to get a bra which fitted because the implant was 'rather a funny shape'. She was conscious of it being 'not like my own breast.' When her youngest daughter came for a cuddle, she said to her mother, 'It's not very comfortable on that side.' AH was offered corrective surgery but was reluctant to accept it. She felt that her sexual identity had been permanently affected.

Well, I suppose while I've come to terms with it, I'm never going to feel happy with it. It still takes me by surprise sometimes. I forget I've had it done and then suddenly I remember or physically I'm reminded or something and I find that sometimes quite overwhelming, you know. Although it's quite overwhelming, it's not as demolishing as it was initially.

MM did not particularly like her appearance after mastectomy.

It (mastectomy) is not particularly pretty but at the same time if you can live with it it's fine. If it's important and also if you are big busted, you must feel terribly lopsided. That must feel awkward.

EM felt that her appearance after mastectomy was not as bad as she had anticipated.

I was rather dreading looking at myself because I didn't know what to expect. It wasn't till the first or second day after the operation that the nurse took the tape off. I hesitated about taking my top off because there's a full length mirror in the bathroom at the hospital. I thought, 'Oh I don't want to look.' I thought it was going to be something really awful. It wasn't a quarter as bad as I'd imagined.

MH did not want to look at her scar initially.

I didn't want to look at it at first. I saw my back first in the bathroom. After a couple of days I got a bit brave about it. I thought, 'I've got to do it sometime, here goes.' Then I thought, 'Why was I bothered about that?'

Lumpectomy did not seem to have the same devastating effect on body image as did mastectomy. However, five of the eleven women with lumpectomies were concerned about their body images.

I don't like the look of my breast. It's as though something has taken a big bite out of you. I think my breast looks like a tattie scone. JL

MP felt that she had a bad scar after her lumpectomy.

I feel mine is quite a bad scar. Hers (fellow patient) was quite neat. I was envious of that. See the big ridge I've got (shows scar). When I've looked at it I feel a bit sort of sad but then I think, 'It's best gone.'

EL was anxious in case she had to have a mastectomy. Her self esteem had already been damaged by divorce and she was beginning to feel secure in a new relationship.

The thought was in my mind that it (mastectomy) could happen. I'm a single person. I'm sure that matters. I mean if they'd said to me that the breast had to come off, I'd have had second thoughts then. I think that would have worried me.

To what extent did breast implants and prostheses become part of the women's identities? Were they viewed as stigmatising or accepted as part of self? Kelly (1992) found that ileostomists recognised themselves as a different human being from their previous selves and from others. Their comments reflected an awareness that these differences were undesirable and likely to be appraised by others as undesirable. However, there were positive aspects to the situation.

The positive aspect is not based on the stoma, but rather on a broad conception of self which has been threatened by a major debilitating disease and which has been saved by, or has survived as a consequence of surgical procedure. ... the changed body is the price of the survival of self. p. 399

Some of my respondents' self consciousness about changed body image was alleviated by a breast implant or an external prosthesis.

Six women had internal insertion of silicone breast implants. There were difficulties with three of these implants, and one had to be permanently removed. Three women later felt that their implants enabled them to feel more normal. PK was pleased with her breast implant after some initial difficulties.

It's a much better shape and everything. It's tidied it up. I had the big loose flap of skin under my arm. He's (surgeon) taken all that away. It looks much nicer. I see it myself now. My husband is quite pleased. He said, 'You've got quite a bump there now instead of being lopsided.'

HM had problems with infection after insertion of her tissue expander but said that an internal implant made her feel more normal.

I think it will make you feel less mutilated, but if this infection doesn't clear up and they have to take the tissue expander out, it won't be the end of the world. I'd rather have a silicone implant for cosmetic and psychological reasons. If it's under the skin, something near enough to the shape, I think it will make you feel much more normal. I will certainly feel much less interfered with. You're not so conscious of it or having to remember the prosthesis.

Initially, JJ felt that a breast implant reinforced her feminine identity. This mattered to younger women like herself.

I feel normal. I don't feel different. Perhaps if it was ten or fifteen years in the future my thoughts may be different. I think it's important to look and feel normal.

However, several weeks later, she became worried about the appearance of the breast and later had corrective surgery.

I've no complaints other than they've made it (implant) too big. I've tried to disguise it. My own breast is much lower than this one. If I really tighten my bra straps to pull this one up to equal, it's extremely uncomfortable. I think I would want something done with it because it's quite noticeable especially with a blouse. Dr C said that getting well was more important but I think your overall appearance is important. It sounds very flippant to say, 'It's too big ' but I think I would want something done about it.

MW had her infected breast implant removed. She later had plastic surgery to give the breast a more normal appearance.

It's quite a good shape. It's a better shape than it was before (shows breast). I'm going to see about having a proper prosthesis made because the swelling has gone down now.

CN had had bilateral mastectomies but unfortunately developed metastases before her implants had been inserted.

2eii External Prosthesis

Ten women who had had mastectomies were fitted with external prostheses. Five were pleased with these. JN, an elderly widow, liked her 'normal' appearance when wearing her prosthesis.

I'm very pleased with it. One lady I'm friendly with said, 'I can never remember which side it is you've got away. I said, 'Well, have a choice.' One lady will insist it's my right side and I haven't disillusioned her and said, 'No, it's the left side.'

JH had a second mastectomy 16 years after her first. She felt she was given little choice of prosthesis and the one she was given did not boost her self confidence.

With having a bilateral mastectomy, I've got two prostheses. There was no choice of prosthesis. I came home and I thought, 'That's quite heavy with the two prostheses.' I thought, 'I'm not really happy with this.' I went up and saw MW at BCMA. The time she spent with me was amazing. In the end she said, 'This is quite a new one.' It was just like a shell. That was the best one for fitting the cup of the bra. I phoned B and asked for X type. The fitter said, 'They are

much more expensive than we normally provide. We couldn't afford to give all our ladies that type of prosthesis.' I felt guilty that I had gone to BCMA. That shouldn't be. I've got my new prosthesis in today. It's far lighter and it doesn't ride up. I felt delighted with it. I think it's a bit unfair not to be shown the full range because it's a big operation for a woman. I think it's part of you, more so than someone who wears glasses all the time. When you have that type of surgery, you are wanting something that's going to make you feel confident.

Five women found difficulty adjusting to a prosthesis. SS complained that it did not feel part of her.

As I say, it's just foreign at the moment. It's better than a comfie because the comfie just makes you uneven. I suppose the comfie gives you a false feeling whereas you feel you've got some weight in your bra when you've got the prosthesis in, but when you bend forward it comes away from the skin. You're aware of it but I suppose like everything else it should come through time.

EM found her new prosthesis rather unnatural.

The longer I put off wearing it the less I'll want to wear it. It doesn't move with your body the same. It's difficult to come to terms with but I thought, 'The oftener I wear it the more used I'll be to having it in and pretty soon it'll just fit like second nature.'

MB was unhappy with her prosthesis.

I'm not really happy with it. When I'm getting my photograph taken it seems always to pull my dresses. I can always see it in the photographs and I just think it's not right.

An elderly woman, DW, worried about her appearance.

It's taking a wee while to get used to it. I got it on Thursday but by Thursday night I was quite tired. I thought, 'This is wearing.' It's just the feeling of it. It's different. She said it was more of a natural look, so I'll just have to try it. I suppose it looks better. She just showed me the one kind and of course I thought, 'Well that's that. That's what you get.' You do like to feel confident, so that nobody will notice unless you tell them.

RW was happier with her prosthesis once a pocket had been sewn into her bra to prevent it slipping out.

I've got a bigger prosthesis on this side and I'm more conscious of it. I'm not so bad now because I have the pockets in my bra. When I only had the one, I never had a pocket in my bra. Quite often when I was gardening this would come out. That used to be quite embarrassing. Sometimes even doing (nursing) a patient, it would slip out.

SM was embarrassed wearing a prosthesis after mastectomy. She did not like taking it off at night and had felt uncomfortable going into the water on holiday

because the prosthesis showed through her T shirt. She did not feel confident enough to wear a bathing costume. She had sometimes forgotten to wear her prosthesis when going out and found that situation embarrassing. For the same reason, S had not shown her prosthesis to her teenage children. She was considering having a breast implant to boost her confidence.

2eiii Hormone therapy and sexual identity

Sixteen women suffered side effects from hormone therapy. The majority (12) had menopausal symptoms of hot flushes and sweating which in severe cases disturbed sleep. Three patients had nausea and vomiting and one a vaginal discharge. As well as causing physical discomfort, the menopausal symptoms were another reminder of the threat of breast cancer to their womanhood. JM found her hot flushes and sweating embarrassing but recognised that she had to persevere in taking Tamoxifen.

It (Tamoxifen) gives you flushes and the water just pours off you. If I was to walk into a crowded room or into a shop, all of a sudden you feel this perspiration running down your back. It's horrible. I've spoken to them about it at the hospital. I've got to take it. I wouldn't think of not taking it. Am I on that for life now?

Having had an oophorectomy, SR was worried that she might have hot flushes when at an important business engagement.

I've had the flushings. Tomorrow, I'm going to this survey with the Chairman. He's picked a group of people. I thought, 'I hope I don't have it when I'm with him. This is going to be terrible.' At work it doesn't really bother me. Everybody knows at work. I'll just be glad when it does wear off eventually.

MM worried about signs of an early menopause. Nobody had explained whether Tamoxifen would make her periods stop permanently.

I haven't had a period. I've never had that before. They did say that they would be irregular but I didn't know to what extent. They did say that your hair might be coarser. I didn't find that. I suppose you have the feeling of going through an early menopause. I haven't had flushes. The only thing is the period. I do have that sort of funny feeling that there's a change going on in your body. I feel I should be waiting on this period and it's not come.

EL did not like the idea of Tamoxifen causing menopausal symptoms.

I started on pills on Monday, Tamoxifen. I wasn't very happy about that. I don't like taking pills unless I have to but they recommended it. They said there could be side effects. They said they might bring on flushings. I feel warm enough sometimes without that.

As a young woman of 28, LB wondered if hormonal changes during a future pregnancy might cause a recurrence of her tumour.

I suppose if you became pregnant there would be a change in your hormones. Would that be a potential risk again? Certainly we weren't thinking of having children at the moment but in the future. It's sort of at the back of your mind, 'Am I going to take the risk and become pregnant?' You think, 'Could the difference in the hormones bring on another tumour?' They said there wasn't any link but ... I think I'll just get through the next bit and think about those sort of things later.

JH worried about the effects of Tamoxifen on her femininity.

Friends of my age are on HRT. The impression I was given about this Tamoxifen was that it's a hormone blocker. I thought, 'If people of my age, my friends are having their hormones replaced and I'm having mine blocked, what kind of effect is that going to have on me?' You know, you first read about this HRT being the elixir of youth. I thought, 'Gosh, the wee drop of oestrogen I've got, they're blocking it. What sort of effect is it going to have?' That's the only thing, the thought of taking it for life.

2eiv Hair loss

Hair is an important aspect of most women's feminine identity. Chemotherapy caused hair thinning or hair loss and this distressed some respondents. Wearing a wig to work was important to AD who could not find one that suited.

I think it's when your hair is falling out that you have the problem. My hair was reasonably short so it didn't look that bad when it came out. I think it's quite traumatic actually losing it. When it's gone it's not much of a problem. I got special permission to go the day before chemotherapy and choose my wig then. He advised me to go for the light one because he said that I would be very pale and drawn after my chemotherapy. He said it would look more normal if my hair matched my paler face. It was just a disaster. It didn't suit me at all. I didn't find the wig particularly comfortable so I really only wore it to work. I felt I couldn't turn up to work with a scarf on.

JB and EW did not like wearing their wigs outside in case they blew off.

I've started wearing my scarf when it's really windy. I'm happier with my scarf on. I'm fed up with this wig. I hope nobody comes to visit us when it's being washed. EW

RW was embarrassed at losing her hair after chemotherapy and disliked her wig.

I lost my hair except for a wee area. It came all white and fluffy. I was like an old witch. I had a wig and by night time I couldn't stand it. I used to take it off. My third son down used to crumple up and cry, so I used to keep it on as long as possible. The wig was sort of itchy. I never felt really comfortable in it. Vera Duckworth in Coronation street obviously wears wigs but they look natural. You see somebody in chemotherapy and it's like a wig. They're too brassy. I was

frightened of it blowing off. I can remember my first night back at work (nursing). I had my cap and this wig. I was quite glad when my hair started to come back in.

MC found her hair loss traumatic

My hair was coming out and it was making me feel sick. Half of it was on the pillow. Between being sick and this hair, you felt as if you were swallowing hair. It is a very traumatic thing for any woman to have lost her hair. They are good wigs and what have you, but even so. I never washed my wig. I never wore it at home. I just wore these wee cap things and sometimes I wore a scarf when I went out. I never wore it constantly unless it was something to do with the caravan club or if I went to a social.

MH was more concerned about telling people of her hair loss than about wearing a wig. As a Christian 'missioner' to the Navy, telling the truth was an important aspect of her identity.

It was all over the pillow, all down my neck and everything. Within a week it had virtually all gone except for a few straggly bits. I just tried the wig on and put the comb through it. I went straight into the NAAFI and I thought no more about it. I was more bothered about somebody saying to me, 'Your hair looks nice.' That did happen, but somehow we worked out having to say what it was. I told them it was a wig. I think we just laughed about it. They have accepted it round here very well. Nobody makes me feel embarrassed about it.

2ev Advanced disease/recurrence and body image

The threat to life posed by advanced disease does not always override anxieties about sexual identity. CB had a recurrence of her breast cancer diagnosed several years previously. She now disliked her appearance, She always took a foam bath to avoid looking at herself, saying she felt 'dirty' because of her cancer. MS regretted losing her breast implant, removed after recurrence. This meant she had to reconstruct her identity for a second time.

The implant was really great. It was almost like not having a mastectomy. That (removal of prosthesis) is something I haven't really come to terms with. It's like as if I've just had a mastectomy this time which I didn't need to face before. They've offered me a reconstruction in two years, but that would mean skin grafts, so I don't know. I'll wait and see. I was very, very happy with my implant. I didn't need to have special swimsuits or bras or anything. It was really good psychologically and it made me get over things because I didn't need further treatment last time. I got over it very quickly. That was why it was a complete shock when it happened again. I don't think I'll have that supreme confidence again, especially having an implant. I'd be worried in case things were developing underneath.

Breast cancer and its treatment may adversely affect women's sexual identities and their relationships. Single women may also be affected since breast surgery may cause them to perceive themselves and be perceived by others as 'incomplete'. Kelly (1991) found that sexual relationships were a source of anxiety for young adults with ileostomies. This was especially true of the unmarried/unpartnered. He noted that the sexual encounter contained the possibility of rejection if the portrayed identity as normal or ordinary is not legitimated. Being sexually active involved significant others in legitimising certain claims made by the self. Some ileostomists chose concealment, others revelation.

Eight respondents expressed concerns about the possible effects of breast cancer on their sexual relationships. Seven were married or had partners and one was divorced but in a steady relationship. Even in longstanding, good relationships, anxieties existed. For example, MM had been happily married for many years but still worried about the impact of her mastectomy on her relationship with her husband.

The first time I went into the Parker Bath (in hospital) there was an awfully nice nurse took me in. I said, 'Funnily enough nobody prepared you for how you are going to look.' She said, 'What do you think you look like Mary? Do you think you look worse than you imagined or not so bad?' I said 'Well, not so bad because I imagined I was going to have a cavity.' I said, 'I've been worrying how my husband 's going to react.' She says, 'Well you know the man you've lived with for 30 odd years, but I can understand.' It was nice to talk to somebody about it, you know, about my husband. I suppose a lot of people don't worry about it but I did. I think that's what it's all about. It's dealing with that side of it.

EM, also married for many years, worried about how her husband would react to her breast surgery.

I thought 'What will I do if he (husband) shows even the slightest twitch?'

SS was depressed when she first looked at herself in the hospital mirror after her mastectomy.

The first day of seeing myself in the mirror, I went through the hankies like mad. Eventually I went to the toilet and had a bubble. One or two of the other women said they wouldn't show their husbands right away. It would have to be when their husbands asked.

She got undressed on her first night home from hospital without hiding or saying anything to her husband about her mastectomy. MW worried about the effect of her mastectomy on her relationship with her husband.

When I was coming home (from diagnostic clinic) I was thinking, 'How is he going to react? How is he going to react to me emotionally after it's done?' I defy any woman not to be worried about that.

MP had been widowed after her husband's long illness. She now had a new relationship and worried about her partner's reaction to her breast surgery.

I thought it (breast surgery) might sort of put him off me but he says, 'No' It makes him feel more. He really is very kind.

HM had had to cope not only with her own breast cancer and mastectomy but with her husband's illness (subarachnoid haemorrhage).

I know that the physical side will never be the same again, but changes are to be expected anyway at our time of life. I'm taking things as they come.

SM was not now thinking so much about her mastectomy, except as she saw it affecting her marital relationship.

Oh I'm not thinking so much about the operation, definitely no. The only time I think about it is with me and my husband. It all takes time. I'm just glad they got it. It's been like a nightmare when you look back.

2f Changed or normal relationships

Important relationships may be impaired by illness. Lynam (1990) found that a cancer diagnosis was perceived by patients as threatening those relationships from which support was derived. Patients were in a new position with respect to others in their social world. They all had to tell their parents, consider how it would affect their children including who would care for their children if they died. Many found it difficult to be in roles previously occupied by their parents, providing reassurance. Her respondents realised how threatening the illness could be to the people they cared about as they too needed to confront the issue of mortality. Lynam noted that some authors have claimed that illnesses such as cancer contribute to an alienation of individuals from persons in their social networks (Sontag 1979, Norbeck 1981). However, her respondents with cancer received support despite marked changes in their appearances.

Breast cancer affected my respondents' relationships in several ways. After surgery, they were temporarily unable to fulfil their normal homemaker roles. Often adjuvant treatment prolonged this period of inactivity because women felt too tired. Work increasingly provides women with an important identity outside family. Breast cancer treatment impinged on my respondents' capacity to work. Returning to work was important in boosting morale and self esteem, especially as most work colleagues were supportive.

Women worried about how partners would react to breast surgery. A mother is an attachment figure for her young children, providing love and security and a role model for her teenage daughters. My respondents were less able to provide security to their young children because they felt vulnerable themselves. Some teenage daughters beginning to discover their own sexual identity, felt threatened by their mother's breast cancer. Some sisters and female friends felt threatened fearing that they may get it themselves. Respondents' concern about changes in their relationships was seen in their desire to protect significant others from anxiety about their illness and in their wish to resume their normal family and social roles as quickly as possible.

Illness also offered my respondents opportunities for increased richness in their relationships because of their increased awareness of how much others cared for them. Quint (1963) found that among 21 women adapting to mastectomy, increased richness in relatedness was reflected through experiencing others expressions of caring, feeling a closeness to others and sensing a receptivity in them. Combs and Snygg (1959) noted that

It may be true that traumatic events in our lives were only traumatic because of their relationship to the more fundamental and basic feelings about self, acquired in the prosaic humdrum of daily life in a family setting. Thus the death of a grandfather might be accepted with little or no trauma by the child who felt adequate and accepted in his family but would seem an irreparable loss to the child for whom such a grandfather represented the only love and acceptance in a family situation where such treatment was lacking from mother and father. p. 135

All my respondents experienced some changes in their relationships during their illness. RW's husband was initially upset and unable to support his wife when she developed a recurrence.

I think this kind of floored him again. He couldn't come near me when I said, 'I've got to go for more tests.' I just couldn't console him at all. When he came to take me home from the hospital he said, 'My stomach has been turning over all

day.' I've always maintained that it's worse for the relatives. I know it's bad for the patient. I always feel sad for the relatives who come into hospital when patients are maybe dying of cancer. I think there's an awful loneliness when they go away home. He appears to be fine now.

Many relationships were more supportive to patients than before their diagnosis. Some were negatively affected by the illness, while a few were lost altogether.

Summary

Respondents reported that six core aspects of their identities were threatened by breast cancer.

Prior to diagnosis, they had a sense of permanence and future security. While mortality was a covert aspect of self, it had not previously been brought into sharp focus. They now had to strike a balance between excessive fear of mortality and denial of their increased vulnerability.

Many respondents had not previously been seriously ill. They now underwent deep changes to the concept of themselves as healthy, feeling mistrustful of their own bodies. They regarded cancer differently from other illnesses which seemed more controllable, less sinister and used various defence mechanisms before accepting the diagnosis. At what point in their illness history could they be confident of their health?

Women had previously considered themselves competent and independent. Now they were uncertain of their ability to fulfil their normal roles and to control their health. Respondents lack of confidence was shown in concealing their dependence and testing their competence.

Respondents had always assumed their normality, that is their acceptance in their various membership groups. After diagnosis, they could not accept themselves in the same way because cancer imposed so deeply on their core identities. Their feelings of guilt were expressed as, 'Why me? What have I done wrong?' Many respondents perceived also themselves as being rejected by a minority of their network members after diagnosis.

Respondents' sexuality which was threatened by surgery (body image), hormone therapy (menopausal symptoms), and chemotherapy (hair loss). Older and younger

women and those with advanced disease all felt lack of confidence in their sexuality. Prostheses relieved self consciousness for some. Others found it difficult to adjust.

Women's longstanding and close relationships were threatened. They felt less confident in fulfilling their roles as partners, mothers, homemakers, workers and worried about network members' reactions to their illness, even when relationships had been good. All respondents recorded some changes in their relationships.

Chapter Four

The Nature of Social Support

This chapter's data support the definition of social support as those attitudes and actions of others which maintain individuals' identities. People's identities are maintained in everyday life by their attachments to and interactions with significant others. Attachments provide security, evidence of esteem and emotional commitment and promote self worth. Social interactions are patterned by responsibilities and expectations associated with social and work roles. This chapter considers the role of informal support in maintaining patients' identities during illness. The role of professional support is considered in chapter 7.

1 The role of informal support in maintaining and changing identity in illness

In illness, social support buffers people's identities against threats to their well-being. It helps people to mobilise their psychological resources by providing information about the threat softening or removing it and helping people to assess their coping resources. In a qualitative study of young adults with cancer, Lynam (1990) defined social support as;

assistance in responding to threats to identity associated with cancer

As they responded to identity threats posed by breast cancer, my respondents indicated that their social network members supported them in various ways.

2 Support in reducing the stressor

Support can change stressful situations by reducing or eliminating threats to people's self concepts. Respondents identified two ways in which informal support reduced the stress caused by the breast cancer diagnosis.

2a Defining abnormality

A defined threat is usually less frightening because knowledge makes coping easier. Diagnosis of serious illness like breast cancer is stressful, but usually less so than coping with uncertainty. Initially, some respondents defended themselves against the possibility of having breast cancer by delaying their reporting of symptoms, denial, distancing, and normalising of symptoms. However, they found this period of suspected illness very stressful. In five instances, network members supported women by confirming that symptoms were abnormal and encouraging them to report to their doctors. JL's, MP's and SR's experiences were typical.

My breast all suddenly changed shape. I showed it to my daughter and she said, 'You'd better go and see about that.' JL

S (daughter) works at the Well Woman Clinic. I said to her 'Have a look at this (dent in breast).' She said, 'I think mum you should go and see about that.' MP

SR was so shocked at her breast cancer diagnosis that she was unable to make crucial decisions about treatment.

My sister was really good. She said, 'You have to have surgery to get rid of it because it can't stay there.' She's very direct. That was how we overcame that part of it.

2b Emotional regulation

Lazarus and Folkman (1984) noted that people coped with crises by problem solving and emotional regulation. Respondents not only had to come to terms with having breast cancer but also with their emotions. Informal support helped them to cope with anxiety, fear and depression in three important ways.

humour.

companionship/advocacy.

comparisons with peers.

2bi Humour

Frank-Stromberg (1986) found evidence of the therapeutic effects of humour among patients with cancer. However, much literature identifies humour as occurring spontaneously, implying that it cannot be consciously planned or taught. In peer groups there are opportunities for spontaneous humour. As people are 'in the same boat', there is less chance of it being used insensitively. When the diagnosis of breast

cancer was made, my respondents were deeply shocked. They also felt very isolated. The camaraderie and humour of fellow patients often alleviated the seriousness of the illness crisis. EC found that sharing the 'black humour' of her situation with the other women was supportive.

We had a good laugh at the breakfast table. I was recounting when you hear you've got it (cancer), you immediately think, 'This is the end. You are finished.' I was thinking, 'Who would I leave my earrings to?' Immediately the rest of them said the same thing. One of them had made her will. They all went through this bit that it was final. This was the end for them and they were putting their affairs in order. Well, we really had a laugh. So it's a very extreme reaction because it's cancer.

EH found that a young patient in the hospital at the same time as herself had a good sense of humour.

S had her operation at the same time as me. She had the other breast off and the implant last year. She's only 32 but she wasn't sad. She used to laugh and joke about it. You've got to laugh about it.

Humour helped SS to forget about her cancer for a while.

On Tuesday, three of us were at the hospital. We had quite a laugh there. There was a right talkative sort of person that took it off your mind.

MB's husband worked at a builder's near the hospital and waved to her as he passed to the amusement of other patients.

He used to come round on his motor cycle every morning and wave to me when I was in the hospital. The lasses all said, 'Just because the lady loves Milk Tray!' It cheered everybody up.

There was occasional humour in the lives of even the most seriously ill. ED had advanced cancer and was often very tense and anxious.

I was sitting at home and I said to my daughter, 'I feel awful.' She said, 'Just sit back mum. Dynasty is coming on (TV).' I miss Dynasty!

2bii Companionship/Advocacy

Respondents reported they felt particularly vulnerable when attending clinics. They were anxious then about the possibility of bad news, often felt unable to ask questions or remember what the doctors had said. Eleven relatives and friends regularly accompanied patients to clinic appointments. This was supportive because respondents' anxiety meant they were unable to think clearly. Relatives or friends could ask doctors or nurses questions and remember what was said.

Patients were often unwilling to show their distress to professional staff but could express it to a close friend or relative. This assisted in the 'emotional regulation' discussed by Lazarus. JL's husband calmed her anxiety about clinic attendances.

I went through all her staging with her. I went everywhere with her. Even when her biopsy was taken, she had to have me in the same room.

JM's husband also attended clinics and helped with a treatment decision.

When I was worried about the swelling under my arm, he came up from his work and took me up to the hospital. When I went back to clinic last Wednesday to see Mr D (surgeon), my husband was there as well. He and I decided between us that I wouldn't go in for the trials. Being in the trials is like taking a risk. He (husband) didn't think it was very fair putting that onus on anyone.

SR appreciated her husband's presence at diagnostic clinic.

D was sitting in the waiting room. It was Dr G and the first thing he said was, 'Are you on your own today?' I thought, 'Oh gosh. He has got bad news to tell me.' I goes, 'I'm not on my own.' D came in and Dr G tried to break it gently.

AC's husband felt guilty because he had not been present when his wife had received distressing news.

The very first appointment was when I saw Mr D and he told me I had breast cancer and R wasn't with me. I had to phone for a taxi to get me home and he felt rotten that I was on my own. The only other time that I was on my own was when one of the doctors let the cat out of the bag that it had travelled up to the clavicle. I was sitting on the bus coming home and I thought, 'Why is it that when R is not with me, I get bad news?' He comes along every time now.

Relatives' offers to accompany patients to clinics were not always accepted. Sometimes patients felt unable to share their anxieties. EC's husband took her to clinic appointments but did not go into the room with her, at her request.

I know some of them want their husbands there. He'd be a great support if he was there, but I didn't want him. We're all different.

2biii Peer comparisons

Many respondents (15) compared their own situation with that of fellow patients who seemed to be coping well with their treatment. These comparisons reassured them that they would be able to cope.

The patients impressed me with how well they were coping. AB

When you see the rest of them having chemotherapy you say to yourself, 'You've got to keep on going too.' I had a phone call from J (patient). She's getting her chemotherapy. J is doing fine. JC

3 Support in maintaining/making changes in identity

Combs and Snygg's (1959) alternative to changing the stressor was that the individual must make changes in his/her self concept to cope with the crisis. Lynam (1990) noted that threats to identity were a longer term issue for her participants and support needed to deal with them was usually derived from their informal networks.

My respondents indicated that they were faced with six main crises to their identities associated with their breast cancer experience. Coping with each crisis meant a re-evaluation of self and acceptance of changes to self. Different kinds of informal support were needed. Respondents identified six main types;

- 1 Emotional support
- 2 Companionship
- 3 Practical help
- 4 Opportunity for confiding
- 5 Experiential support
- 6 Sexual identity support

Some or all are illustrated in the following sections in relation to identity crises.

3a Support in facing uncertainty/mortality

Most respondents recognised that breast cancer is a life threatening disease. Since no guarantee of cure could be given to them, they needed to confront their own mortality, cope with the uncertainty of their future, fears of recurrence and develop a positive attitude towards the future.

3ai Confiding

Wills (1985) maintained that an important element in esteem support was the experience of feeling accepted and valued by another person. By receiving acceptance and approval from significant others, a person's own self-evaluation and esteem was enhanced. This type of support would be expected to have its

greatest effects for persons under stress. Wills also noted that people in crisis needed to express their feelings and anxieties to those who would listen with understanding, show empathy, whose relationship with them would not be affected by what they said (unconditional regard), and whose feelings they did not have to protect. My respondents named husbands, friends and peers as their main confidants, although four identified their mothers and one, a daughter, as confidants. Women sometimes chose not to confide their fears about dying to those closest to them to avoid causing them anxiety. Eight women whose husbands/partners were their confidants seemed to have very close relationships with them. AC had discussed the possibility of her death with her husband.

He's been very, very good because he's talked about it whenever I've wanted to talk. If I've wanted to talk about even the blackest side of things before it was confirmed that it was localised, he was prepared to talk about that too. I found that extremely helpful. Obviously things go round in your own mind. I didn't want to get it out of proportion. Then we'd come back to the lighter side. I'd say, 'It's not necessarily that, but we've faced it and we know how we are going to deal with it'. He had the chance to voice his feelings about it as well.

SR was similarly able to express her fears about her survival and receive understanding from her husband.

D and I are pretty close. You are never frightened to tell D anything. Nothing upsets D whatsoever. When I was crying I said, 'I'm stupid'. He said, 'You're not. You are allowed to cry. You've never had anything like this.' I said, 'Do you think I'll survive this?' He said, 'You'll survive anything. You've survived me for 15 years.'

Ten friends became confidants.

I've got a friend at work. She lost her husband through cancer. I didn't like to tell her that I was going for a mammogram but she asked me. She's got a positive attitude. She knows, God willing, I'm going to get better. SS

There's lots of people I feel safe enough with, that I could ring up and say, 'I need a chat.' JJ

You can talk to friends. One of my friends is a health visitor. MS

Two of the four husbands of women who chose friends as confidants were ill. MS, wanted to protect her husband from any anxiety associated with her cancer. MB did not always get on well with her partner. CB was divorced and unable to confide in her family but confided in a friend.

I've got four sisters and I can't talk to any of them, whereas I can talk to K. She's more like a sister to me. She's accepted me as a friend and everything with it whereas my sisters won't talk about it at all.

PY could confide in her daughter.

I can talk to her. She'll sit and hold my hand.

3a ii Experiential support; upward comparisons.

Many patients had friends (10), relatives (8) or work colleagues (5) who had had breast cancer. These people provided proof that it was possible to survive the disease. It was most helpful if the person had survived for several years, since recurrence then seemed unlikely. LF who had kept in touch with her hospital peers would also have liked this kind of support in facing up to her fears of recurrence.

It would be good if M (counsellor) could put you onto a lady that's been through it all, but a long time ago. It's not just happened to her. That would give you the confidence to see that she's well and happy. It would take some of the stress away.

In three instances, mothers provided positive role models for their daughters.

My mum is very good. My mum had her breast off when she was 38. MW

Two women had sisters who had recovered from breast cancer.

My sister has had two mastectomies. I do feel reassured that she has been through similar surgery, but she didn't have any form of treatment after her operation. AB

SL had a sister in India who had made good progress after a mastectomy nine months previously. However, it was too early to say that she had fully recovered, and SL remained very anxious about her own prognosis. MM's daughter in law's mother had had breast cancer and offered reassurance.

The woman is wonderful, so cheery. She said, 'Look at me. If I can go through it, you can go through it.' I have Catherine phoning me back and forth. She was wonderful to me, answering any questions at any time.

Some friends who had recovered from the disease had not previously chosen to reveal this but were now willing to do so because respondents were 'in the same boat'.

I know quite a lot of people who have had breast cancer and who have made perfectly good recoveries. That's what I'm planning on doing. HM

3aiii Experiential support; downward comparisons

Downward comparisons enable people who are uncertain of their own positions and their own futures to feel more secure. My respondents reported downward comparisons less frequently than upward comparisons. Four patients compared their situations with others whom they felt were in some ways worse off than themselves. JL was feeling depressed and anxious during her treatment for breast cancer. She reassured herself by comparing her own situation with that of others who appeared to be having treatment which was more difficult to cope with.

I met some of them who were in with me and they were getting worse treatment than me. They were getting implants and kept in the room for the wires (radiotherapy). I couldn't have stood being shut in a room for a week, not on my own. I kept saying to myself, 'You are not going for chemotherapy where your hair would fall out. You're not going for an implant. You're only getting what you are getting. Get a grip on yourself.'

AC had an inoperable tumour, treated initially with hormone therapy and later by radiotherapy. She felt uncertain. She was pleased not to be having surgery, but she worried whether her treatment was sufficient to cure her cancer. She tried to reassure herself by downwardly comparing her situation with that of a fellow patient.

I keep telling myself that I'm so lucky in that I'm on Tamoxifen because Y who I made friends with the two days that we were having tests, had the operation to have the breast removed. She's had the lymph glands removed and she's going every day for radiotherapy. I thought, 'Goodness I'm lucky.'

JC was having a course of intensive chemotherapy which caused severe side effects. Since the position of her tumour made it inoperable, JC knew that it was important to complete as much of the chemotherapy course as possible. She encouraged herself by making a downward comparison of her own progress.

If I take another three chemotherapies, that will be ten out of twelve. I'll have done very well, because they said down there that the average is eight. Most of them can't go past eight or nine, so if I take the tenth one I'll do very well.

Two patients found themselves held up as examples, a form of downward comparison. MM was a keep fit enthusiast who rapidly returned to keep fit activities.

There's a lady who works in the canteen. She had her breast off six weeks ago. She didn't swim or do much. Everybody says, 'Look at M.' It makes me feel terrible, although I don't mind being held up as a shining example.

JW gave support to others as a church visitor and she showed others how to cope with breast cancer.

I felt as if I was a helper myself with some of the women. If they were down, you'd just tell them to think positive and things like that. Sometimes you really helped them, I think.

3aiv Facing up to mortality with the death of a peer

When one member of a peer group relapsed or died, this put a strain on other group members, as with MW. However, facing up to this reminder of their own uncertain future was in a sense therapeutic to group members.

We lost one girl. Her daughter phoned me and said her mother wanted to see me. I went into hospital and it just wasn't A any more. It turned out that it (cancer) had travelled to the brain. I went every time I was up there to see her.

MW was able to distance her own situation from that of A because the latter had had her breast cancer for several years before diagnosis.

We all went to the funeral. It came to light since she's died that she'd had this lump for ten years. I'm not surprised that it was elsewhere. Okay it did bring it home. We actually had someone at the funeral turn round and say, 'You girls must feel lucky. There but for the grace of God go you.' We couldn't say anything because we'd all thought about it anyway.

3b Supporting a healthy identity

Being treated by others as well women, was important in restoring respondents' identities as healthy people. Two important steps in this direction were;

finding healthy role models.

finding acceptance as well women.

3bi Finding healthy role models

People often compare themselves with others who have experienced a particular crisis since the latter can act as role models, giving indications as to how they may feel, look and what they may be capable of doing in the future. Many respondents knew someone who had recovered from breast cancer and showed all the signs of good health. JJ who worked in a family garage business, knew three customers who had had breast surgery. She gained confidence from their apparent ability to cope and to return to a normal lifestyle. She also had a neighbour who was leading a normal life after breast surgery

There's one lady who lives up the road. She went through it five years ago. You would never suspect it. She looks like a really healthy person. That gives me confidence knowing that at some point, she was going through what I'm going through.

PK had a golfing friend who had had breast surgery and who encouraged her. She found her club friends' frequent visits and phone calls supportive.

I have a friend at the golf club who had this done two years ago and she's saying, 'You'll get there.' She's looking super. She had a mastectomy and she had the implant put in. She wears the most beautiful sleeveless dresses and low necks and you would never know. Another friend, M had a mastectomy in October. She's back at the golf club, playing golf. I've been getting confidence from speaking to these people actually.

Five women had supportive work colleagues who had had breast surgery.

I've got a friend who I work beside. She's had a full mastectomy. When I found out that I had breast cancer, I went along one dinner time when she was on her own. I'd never heard of Longmore before and I asked F if she'd gone there. She said 'Yes, you'll love it. The people are so nice there.' If I ever feel down I just need to phone her up. SR

One of the advantages of being in a specialist breast cancer unit was that patients who had recently been diagnosed or had their surgery could see others being discharged and gain confidence in their own recovery. Fellow patients who had been through similar situations could provide experiential support and understood how it felt.

You see the ones at the different stages and you see them going home. You think, 'Right, I'm next.' The ones that have just come in, you speak to them and you say, 'How are you getting on?' It really helps you. When I got fitted with a prosthesis, the women in one of the other wards said, 'Come up and show us.' so I had to go and show them. They said, 'That looks great. You would never know.' I had seen someone else too when she went home and I thought, 'That looks great.' There was a girl in hospital at the same time and she had had the implant done and she was so proud of it. So I'm looking forward to getting the final job done and seeing what it's like. PK

SL had befriended another patient who was ahead of her with her treatment and could tell her what to expect.

Eileen is wonderful. She's getting an implant and she started radiotherapy before I did, so she was always ahead of me. I would phone her and say, 'Tell me what's happening.' So she would tell me, 'It's nothing to worry about. It's quite simple.'

3bii Finding acceptance as well women

Lynam (1990) found that when interactions emphasised the illness and excluded other aspects in individuals' lives, they created problems within families or at work. Respondents did not want to be treated as sick people when this was no longer appropriate. Women wanted to resume their normal roles and for their network members to behave towards them as before. Eve C's husband and son regarded her as having recovered from her mastectomy. She had resumed all her normal household tasks.

Oh yes. My husband certainly thinks I'm back to normal. I'm quite able to do everything. He (husband) has been excellent really.

3c Supporting autonomy/independence

My respondents were supported in regaining their autonomy and independence both through formal and informal support. Respondents' autonomy was promoted by informal support in two ways;

Temporary help in role fulfilment

Support in treatment decision making

3ci Temporary help in role fulfilment

Fulfilment of social roles is an important part of identity, providing sources of esteem and social status. Any threat to fulfilment of such roles is therefore a threat to identity. While people are willing to accept temporary release from role responsibilities, they usually begin to resent their dependence on others and to suffer from low self esteem if it continues. My respondents' network members offered them temporary help with unmanageable aspects of their social roles with the implication that they would soon be able to manage without help. Women accepted this support. They enjoyed a period of being cared for and took this as a sign of affection and concern. Husbands were particularly helpful in this regard but sons, daughters and neighbours also offered practical help. Men of the family often took an unaccustomed turn at doing housework.

They (husband and sons) have been very supportive. They had the week when I was in hospital and they had to chip in and do a lot more than they normally would do. My husband has been protective. I've got to be a little flower and just take it easy. I get to make the coffee but that's about it. He's been let off his work to look after me. EM

SI had normally done most of the housework despite having a demanding full time job. However, her husband, son and daughter gave her a lot of practical help after diagnosis.

The family have been absolutely wonderful. They really spoilt me. They managed quite well. In the past I feel they've been dependent on me for lots of things. My daughter tries hard but she's a slow learner. That was a disadvantage I had but she has stretched herself a bit more. Whatever she can do, she does.

While giving practical support, one man had made his dislike of housework obvious.

He can cook, do housework, whatever he's called upon to do. He doesn't particularly like doing it but he will do it. MM

JL's husband had also helped his wife with personal care.

When I came home, he had to help me out of chairs and that. I couldn't possibly let him go back to work and be like I am, on my own all day.

Nine sons gave their mothers practical support with housework, doing about as much in this respect as did daughters. Margaret M had sons aged twelve and ten, but despite their youth they had tried to help their mother in small practical ways.

The kids have been keeping their rooms tidy, making their beds and putting washing in the bins. The boys have not been upset at all. I've said nothing you see, and they've just been coming and going. I think it's your attitude too, if you're positive, they're okay.

Mary M shared her enthusiasm for fitness with her son who found an ingenious way of helping her with her arm exercises after her mastectomy.

My son G helped me a lot because he has left hand weights and he used to make me pull the hand weights and stretch up the wall. 'Come on mum', he'd shout. He was just as determined as me you know.

Eight daughters offered their mothers practical help on their discharge from hospital. For example, PY's daughter was staying with her mother since her illness.

B is staying here with her boyfriend and the baby. They feel they don't want to leave me on my own. I've not got to do a lot of heavy things. I've got to take things easy. She does the tidying up and the washing.

EH's daughter gave practical help

D does all the cooking and all that kind of thing.

Four sisters gave practical support. HM's husband had had a subarachnoid haemorrhage just before her breast cancer was diagnosed. Her sister came up from Oxford to help.

I've got a sister who is staying with me until the middle of September because she's a college lecturer and she's not married. She does the cooking basically and she does what's necessary. It's worked quite well.

HC was elderly and lived alone. Her sister came up from England.

That was the biggest help of the lot. I couldn't have managed on my own I don't think.

Seven mothers gave respondents practical help. When there were school age children it was helpful if mother stayed and helped with their care. JJ had two school age sons.

My mother moved in with us for about a month. She's always on the phone just about every day in life.

MW had arranged for her mother to come.

When I'm in hospital, my mum is going to come and be with the kids.

Many neighbours had given patients practical help since their illness. Other researchers have found that neighbours are supportive in a short term crisis, and are well placed to help since they live nearby. JC, PK and EH were quite surprised to find their neighbours so helpful, although they had always been on good terms.

The neighbours have been very good. They are always at the door asking if I'm needing anything. Really I never mixed much with the neighbours. It's amazing when you are ill how helpful people can be. They say, 'Do you want milk or do you want anything done?' JC

They've been popping in and asking me if I need anything. PK

We're not people who've been in and out of each others' houses but my neighbour on the ground floor has been great coming up and down and everything. EH

DW and HC were elderly. DW lived a fair distance from her local shops, so a neighbour took her shopping. HC was unable to maintain her garden, so a neighbour took this over.

Friends provided mainly emotional support, companionship, confiding and peer support. However, a few offered practical help. MW's friend was a district nurse like herself.

I've got a friend who said 'I'll bring you a seat in for the bath.' My bath is quite low. She said, 'I'll bring you a seat just to put over the edge of the bath. At least if you feel you are wobbling, you can sit down and have your shower.'

The workplace provides people with an important identity outside of the family. Getting back to work boosted my respondents' morale and self esteem especially as most of their work colleagues had been supportive during their illness.

3cii Support in treatment decision making

Making decisions is an important part of autonomy. My respondents needed both professional and informal support in making treatment decisions. Women usually involved their partners in making decisions about cosmetic treatments such as breast reconstruction. However, in only one instance was a family involved in making a treatment decision about whether to enter treatment trials. Before making a decision about breast reconstruction, MW wanted to talk to someone who had had similar surgery. There was nobody in this position in her hospital peer group.

I phoned BCMA and they gave me the number of someone who lives in London who had had it done. She explained how she felt. She said she had got a very good reconstruction and went back about four months after and they sewed a nipple on for her. She said it wasn't successful. She said she now has a plastic mould for the other nipple which she puts on. She said, 'You are in a lot of pain after the operation but they control it for you.' She couldn't lie on her back for four months. She said, 'Do you really want to know it all?' I said 'Yes, I can't face things if I don't know what I'm going to.' She said, 'Any time you want to, just phone, if you want somebody to talk to.'

MC's decision about whether to have a breast implant was influenced by a fellow patient's negative experience.

I went into the ward and I had made up my mind that if I could look natural at the end of it all, I will. I'll just go in for it. There was a lady in the corner. I says, 'What are you in for?' Her arms are all swollen. The implant she had got had moved seemingly down the arm. It all went wrong. That just convinced me.

3d Support in facing isolation/overcoming stigma

A sense of belonging or social integration is important when identity is under threat and new aspects need to be developed. However, people in crisis often have a sense of being alone in this situation. Lorde (1980) maintained that invisibility was associated with powerlessness.

If we are to translate the silence surrounding breast cancer into language and action against this scourge, then the first step is that women with mastectomies

must become visible to each other. For silence and invisibility go hand in hand with powerlessness. In addition, we withhold that visibility and support from one another which is such an aid to perspective and self acceptance. p. 61

3di Companionship of peers

Many patients (15) spoke of 'being in the same boat' as others with breast cancer. This feeling of camaraderie among patients sharing a crisis, decreased their sense of isolation and difference. In the peer group patients shared their ups and downs. MM commented;

We went through all the tests together and jollied each other along. They've had their ups and downs but basically they've been fine. When they see you smiling, they say, ' Well if she can smile, I'll smile.' If they can cope, you can cope.

ES felt that although she met people with cancer recurrence, the advantages of peer support outweighed the disadvantages.

It's not a case of 'I've got cancer. I'm very ill.' Everybody is very ill. You're no worse or better than anybody else. I can almost imagine that when there were bombs and air raid shelters and things, there were people who didn't talk to each other who got into the same shelters and shared their food. I think if you go into a ward of women with the same problem, you're all in the same boat.

Understanding was an important form of support. Some appreciated not having to explain to fellow patients how they felt because they understood from personal experience.

The camaraderie is not like a hospital, it's more like a little community, where everyone shares a bit of themselves with someone else because you've all got the same thing. Everyone has the same sort of feelings towards it and how they are looking at the future. I feel it helped me to face it better because I wasn't isolated and I wasn't always having to explain how I felt. EM

When you are going through something like this, I think it's only natural. It tends to bind you together. It's someone to talk to. Someone who understands really. JJ

The empathy of someone sharing a similar experience proved more supportive than the sympathy of someone who was not. Three patients felt that the experiential support from fellow patients in a specialist breast cancer unit made them feel less lonely than they would be in a general hospital ward.

My first mastectomy was in the X hospital. There was an old lady in the next bed. She'd had a colostomy or something whereas up there (Breast Unit), we were all having the same type of thing. We helped each other you know. JH

You are more or less in for the same thing. You have got something you can all have a wee blether about and give each other support about. In a big hospital, you could be sitting with your breast cancer and there is somebody else with something wrong with their leg. They sound interested but they are not really. MC

The relief is actually sharing with people that have all got the same thing. You can let it all out and tell them. EC

PK mentioned the family feeling of a peer group.

We felt like a little family, especially with the different age groups. You see the ones at the different stages.

The peer group reduced the feeling of isolation of having a stigmatising condition. SS compared the companionship she received from her peer group with the loneliness her mother had experienced in similar circumstances.

At first I thought, 'Oh gosh I've got something that nobody else has got'. Then you saw all the other people and there was nothing different about them at all. Then you accepted it. In my mother's time she felt so cut off and that she had something tragically wrong with her.

MP contrasted the peer companionship she was now receiving with her previous lack of support when caring for her sick husband for many years.

When I went up for my treatment, I met some of the other folk. I didn't have that when my husband had his accident. I felt this dreadful thing had only happened to me. It's been like group therapy. You've got these fears inside you, wondering what's in front of you. They've all got the same fears as you, so you're not different.

3dii Companionship of network members

My respondents felt reassured and valued because their network members had spent more time with them since their diagnosis. This was especially true of friends and more distant relatives. SR had a close supportive relationship with her husband but found she also needed support from a friend prepared to spend time with her.

It probably is friends that you do need as well, just for to take up your time rather than being on your own. When I came out of hospital at first, C was always over here in the morning. It probably upset her day to a certain extent because some days she was here till lunch time. That was good because that was your whole morning filled. Then she'd say, 'When A comes home from school we'll go for a walk with the children and the dogs'. If I didn't have her, well I didn't feel up to going out on my own. She said, 'That's what friends are for.'

JL had had extra visits from her sister in law.

She works full time but she comes every week for a chat. She visited me in the hospital too.

Friends offered companionship and shared interests. AB's friends visited her and went out to lunch with her. PY's friends visited her frequently. EC's friend, L, who lived in England planned to stay for as long as she was needed. EC also had other helpful friends.

L has been very, very supportive. I have another friend, 15 miles the other side of Birmingham. She's been twice. I've got one in Dundee. They're very good. Then in Edinburgh my friends are always offering help. That's what keeps me going. How people manage without friends I don't know.

JW had recently retired from Lewis' department store and was a member of their retirement club.

They were so caring. They've got a retirement committee and I told them. They sent flowers. I got 66 'get well' cards. I go once a month for afternoon tea.

MB had inoperable cancer but was still able to enjoy going to bingo with her friend. EL was divorced and friends' companionship was very important to her.

I still go dancing. I'm going out tonight. We have some good laughs. That's the main thing. There's three of us. Three women that go. We have a good laugh at the men's expense.

MM enjoyed the companionship and shared interest of her swimming and her aerobics class.

I swim every other day and I go to aerobics three times a week. I'm really very fit. When I go to the aerobics class, I'm able to keep up with everybody. I don't go to the over 50 one.

Before she returned to work after her mastectomy, AH valued her friends as people with whom she could do things.

I started to do something energetic every day. I took the dog out and went for a long walk with a friend, did something like that every day. That's really helped, doing some of the things that I'd thought I wanted to do.

DW was a widow living alone but her relatives spent a lot of time with her after her bilateral mastectomies.

We were up at Pitlochry with my cousin and my niece. They were going up and I said, 'I don't like tagging on to people.' They said, 'But it's not our main holiday.' It was an extra holiday, so it was quite nice.

Some sisters, daughters and sons had also spent more time with the women during their illness, as had four mothers. MH had recently been widowed and both her daughters had been supportive. It was difficult for husbands to spend more time with their wives if they were working. However, three husbands had made a point of spending more time with their wives since their breast cancer diagnosis. JJ had two young sons. She had discovered a new dimension to family life since her cancer diagnosis.

My husband is a workaholic. It was terrible, but since this has happened to me and having to go through all this, it brings it home how important your time is. He's decided, and he's been very good he's adhered to it, that he works Sundays only when it's to do with car rallying and nothing else. Sunday is family time. We've done all sorts of things that we should have done years ago. Life is too short. It's sad that it takes something like this to make you take stock of things. It puts your priorities in place.

Two husbands took time off from their work to be with their wives after their discharge home from hospital after breast surgery.

3diii Acceptance as 'normal'

Goffman (1968) noted that stigmatised people could encourage 'normal' people to accept them.

The stigmatised individual may, for example, attempt to 'break the ice', explicitly referring to his failing in a way that shows he is detached, able to take his condition in his stride. p. 141

When women were open with others about their breast cancer, this sometimes encouraged others to treat them more normally. SR told the people in her aerobics class and neighbourhood about her breast cancer and found that attitudes towards her became more positive.

Before, if you had cancer, nobody knew. With my mother it was a hush, hush thing. Nobody ever came out openly as they do nowadays which was really very wrong. I'm going to the shops and I'm meeting all these people that I normally meet. I think I would feel worse if they didn't know what was wrong with me, whereas they all know, so you can have a really good chat.

Concealing the effects of breast surgery from all except their closest relatives seemed to be easier for the women than concealing the fact that they had had

cancer. There was less need to make explicit references to their surgery. The internal implants and external reconstructions gave the women a normal shape which seemed to be accepted by many of their network members without causing them too much embarrassment. JN was pleased with her prosthesis and the effect it had on her figure.

People just don't know. One lady I'm very friendly with said, 'I can never remember which side it is you've got away.' I said, 'Well, have a choice.' One lady will insist it's my right side and I haven't disillusioned her. She said, 'You wouldn't know it's an artificial one on the right side.' I said, 'No you wouldn't!'

3e Support for sexual identity

Respondents had to accept more than the loss of a breast or changes in their appearance after breast surgery. Lorde (1980) described her own reasons for not wearing a prosthesis.

This emphasis upon the cosmetic after surgery reinforces this society's stereotype of women, that we are only what we look or appear, so this is the only aspect of existence we need to address. p. 55-58

Most women were given the support they needed to cope with threats posed by breast cancer to their sexual identity. Partners' support was particularly important to their coping.

3ei *Partners' affirmation of value and femininity*

Many women worried about how their husbands would react to their changed body image and to the fact that they had cancer. MM, who had been happily married for many years, still worried about the impact her mastectomy might have on her relationship with her husband. She found her husband to be very understanding.

I think that's what it's all about. It's dealing with that side of it. I was frightened to take my clothes off when I was going to bed that night. I thought, 'Well, come on M, what are you going to do here?' One of my sons is married and there is a spare bed in the other room. He (husband) said to me, 'Is your arm all right M? Now you don't want me to sleep in C's bed until you feel better?' I said, 'Oh no!' He said, 'I don't mean it like that. I don't want to sleep in C's bed, M, but I just wondered.' I said, 'No'. He said, 'All right, let's get into our bed.' If I'd said 'my arm is too sore,' he would have slept in the other bed but he wouldn't have been pleased.

EM showed her mastectomy scar to her husband and sons when she got home from hospital. She was pleased that he reacted to her as 'normal.' Her husband had also helped her choose a prosthesis.

It made it easier because now all three of them have seen it, the boys as well as him. I realised it wasn't as bad as I thought. Once we got past that, now he just accepts that I'm normal. He's quite taken to the new bit of me as well (prosthesis). He was there when I tried on one or two (prostheses).

SS got undressed on her first night home from hospital without hiding or saying anything about her mastectomy scar. Her husband commented on her neat scar.

When I came home on the Friday, I did exactly what I would normally do every night, got undressed in the bedroom in front of J. I didn't hide it and he's not bothered one bit. The second time, I was getting undressed and he said, 'What a super job they've made of your scar.' He's really been the one that's watched the scar going.

MP, a widow who had cared for her sick husband for many years, worried about the effects of mastectomy on her new relationship.

He says it (breast surgery) makes him feel more for me. It's not put him off. There was a programme this morning on TV. This woman's implant had collapsed and disintegrated and her husband had said to her, 'Oh you'll have to have something done or I'm off.' M (partner) was saying, 'Well what kind of men are they?' Well you must have support mustn't you. If you didn't get it from your husband, it would be terrible.

It was helpful if the woman was able to discuss her anxieties with her husband or if the latter was sensitive enough to broach the topic. MW's husband had said,

That's going to make no difference to our relationship, just because you haven't got one breast. It's not going to make any difference to our sexual life, to our marriage.

AB's husband had commented positively on her new body image.

He tells me he likes my new appearance.

MM's husband had discussed with her whether or not she should have reconstructive surgery.

He discussed the possibility of reconstruction with me. He only wants what I want. He just said, 'I don't see any difference in you M. You are just the same as you were before and if you're happy that's what counts.' Oh no, it's never made any difference to the two of us at all. He's never been put off our marital side of things at all.

BI's husband was very supportive about her appearance after reconstruction.

J's attitude has been super. I would say, 'I don't like the way I look.' He would say, 'Why don't you like the way you look? I like it. There's nothing wrong with it. You're very fortunate. You might be dead now. You've been given a new lease

of life.' That approach is terrific. It doesn't matter what I come up with, he seems to be able to counteract it like that.

Some husbands seemed unsure of how to affirm their wives sexual identities when they came home from hospital. MB made it plain to her husband that she did not want to sleep separately from him after her mastectomy.

Actually he said when I came home after the mastectomy, did I want him to sleep in the other bed for a wee while, in case he knocked me. I said, 'Oh no just sleep beside me and that's it.' 'OK then', he said. 'It was just in case I bumped you in the night.'

MH's husband was surprised at how quickly his wife seemed to come to terms with her breast reconstruction, with his support.

I was more concerned with M coming to terms with it. I thought it was going to take months quite honestly, but it hasn't. I remember saying when she was in hospital, 'Let me have a look.' She wouldn't let me because she was a bit embarrassed with people about. As soon as she came home, she had no qualms about that at all. I think the operation they did, cosmetically, was brilliant. OK, there's no nipple there, but it doesn't make any difference.

MC's husband was supportive when she lost her hair after chemotherapy and had to wear a wig.

My hair loss was very traumatic. I've not got marvellous hair but I think for a woman it's most important. I remember sitting here one Saturday night. I'd just been fitted for the wig. I went up the stair and I had a good wee bubble in the bathroom. I came out and washed my face and put on some make up and put the wig on and came down. My husband said, 'You look a million dollars!' Well there was a holiday weekend with the caravan club. I always remember this fellow saying, 'My, you're looking super and you've had your hair done for the holiday.' It was my wig!

3eii Friends'/peers' affirmation of 'normal' sexual identity

Encouragement regarding the normal appearance of their body shape by peer group and friends was an important step in recovering self esteem. Women sometimes showed their prostheses to their friends and peers, seeking confirmation that they looked normal. JJ showed her friends her breast reconstruction.

They all say, 'You don't look any different at all.' I've shown it to my girl friends. Everyone was keen to see. I'm not shy about showing it to my girlfriends. Of course they were all quite amazed at how normal it looks.

EC was very upset at the prospect of having a mastectomy but was supported by fellow patients who were at a later stage in the process of reconstruction and acted as role models.

Sister said, 'There's three women who have just come in and they're in the final stages (of reconstruction). She got us all together with a sherry. I was still crying and feeling sorry for myself but they were really lovely these women and they told me all about it. I thought, 'Mm, well maybe it's not so bad.'

HM had a friend who had had a breast implant.

I've seen the results. I've got a friend who showed it (implant) to me before and after and it's very good. I think that sort of tipped the balance, as soon as I saw that it was such a good result. I thought it seemed a much more natural result.

3f Support for relationships

Caplan (1976) maintained that the family was important both as source and validator of identity.

A person in crisis or in a period of transition normally relies in large measure on the messages he receives from his social environment in appreciating his own identity. p. 30

People need to be assured of the love of those closest to them, and this need increases in times of crisis. Such attachments provide emotional support, esteem support and a sense of security. Sense of attachment is an important form of support as the person who is supported feels he or she matters to others. Both professional and informal support are needed in a crisis but the latter offers intimacy, security and identity maintenance and thus is vital to long-term coping and adaption.

3fi Emotional support

I defined emotional support as 'expressions of concern', strengthening bonds and reassuring respondents that their relationships were intact. Husbands, relatives, friends, and work colleagues provided emotional support in varying degrees. For example, MM was very upset prior to her admission to hospital for breast surgery and her husband showed his concern.

The morning I was going into hospital, I went into the bathroom, took my clothes off and looked at myself, crying my eyes out. 'M,' my husband said knocking at the door, 'Come on out of there. What's the matter?' He had an awful job coaxing me out, but then I did come out. He made me a cup of tea and I was as right as rain when I got to the hospital door. He's been a tower of strength really.

However, providing emotional support was not synonymous with being a confidant and only 13 women chose to confide their anxieties about their illness to their husbands/partners, 10 choosing friends, and 12 choosing fellow patients. Family members had given emotional support, showing their concern by extra visiting and phone calls. MB had inoperable breast cancer and had just moved from a hotel room into better accommodation with the help of her health visitor. Her mother had helped her to make the flat look attractive by providing some furnishings and ornaments. LB was shocked to be diagnosed with breast cancer at the young age of 28 and had found her parents very supportive. EC's son was very supportive, taking her to hospital for her diagnosis and 'tumour staging' so that he could hear what was being said and ask questions. Three adolescent sons showed extra affection to their mothers following their illness. CB with advanced cancer, got a 'lot of love' from her teenage sons. However, she did not discuss her anxieties about her illness with them.

AH whose family had not recognised her need for support initially, found that her teenage son became very affectionate.

He was the most considerate of all actually. He was the most likely to come and give me a hug. It was more noticeable in that he had been more obnoxious. He really was quite an obnoxious teenager.

BI received a lot of support from her sons although initially, on hearing her diagnosis, they had been very upset,

T has been the most understanding as far as recovery is concerned. He would try and get me out of the chair and say, 'Come on mother, I'll help you. Reach a little bit further.' I'm sure it would have been much more difficult if he hadn't been helping me like that. He had a very real appreciation of the suffering and pain, whereas the others didn't seem to appreciate it in the same way. Having said that the others were very supporting.

SR had a very good relationship with her husband's son by a previous marriage. He stayed with them every weekend and enjoyed it because they treated him as an adult. She had shown him her breast scar and explained to him about her hot flushes. He had been very supportive and had a good sense of humour. Some very young children provided their own kind of emotional support. Their demonstrative affection seemed to compensate for the attention they demanded. All except one woman had friends who had shown their concern by phone calls and visits.

Friends phoned up to see how I was and sent flowers. There was one family and they were wonderful. Anytime I felt in need of anything I could phone them and they would come and visit me. SL

SS valued the spiritual support offered by her church friends.

There's a lot of prayers being said by a lot of people. I'm in their thoughts. You don't think it's doing anything but it does. It brings you through. Sister F was up a few times.

Work colleagues gave emotional support to most of the employed women (23) by expressing their concern, and making them feel that it was all right to take as much time off work as they needed. When AB returned to work after her mastectomy, her colleagues would not allow her to work overtime.

People say, 'It's time you were home now.' I used to work a lot of extra hours. They've been politely indicating that they think it's time to go.

AF had advanced cancer but struggled to cope with a part time job.

The boss is understanding. He says not to worry about the job.

PK worked as a college secretary.

They say, 'Take your full 6 months.' My personnel officer came to hospital to see me. Her mother was getting staged at the same time that I was in. She has had cancer itself, not breast cancer, but she understands it.

LB who had had chemotherapy after her breast surgery received sympathetic treatment from her work bosses.

They said I could carry on part-time as long as I need. They even said a couple of hours a day but obviously I wanted to try and do a wee bit more. C is my direct boss but there are management that are male and they've been really good.

Neighbours also showed their concern. JL had had to use her neighbour's phone late at night.

I had to use my neighbour's phone the night I phoned the doctor. The doctor didn't come till midnight. She's (neighbour) in her 70's but she wanted to know how I got on.

Two women had very close relationships with their neighbours who had become even more helpful because of the illness. JW said,

My next door neighbours are like a mother and father. They've always been like that.

SR appreciated the time her neighbour spent with her during her illness.

I can go to C's anytime. She would come over here. When I was at work we didn't see each other much.

Summary

This chapter's data support the definition of social support as attitudes and actions of others which maintain individuals' identities. Respondents described informal support as reducing the stress of their breast cancer diagnosis and helping them to maintain or change aspects of their self concepts to cope with the crisis. Women identified two ways in which informal support reduced stress; (i) Some network members confirmed their abnormal symptoms and encouraged them to report to their doctors. (ii) They were helped to cope with emotions of fear and depression by humour, companionship, and peer comparisons. Respondents' statements indicated that they faced six main identity crises. Coping with these crises meant a re-evaluation of self. Different kinds of social support helped either maintain or change aspects of identity. Support in facing uncertainty/mortality included confiding in others and receiving acceptance and affirmation, making upwards and downwards comparisons with peers to enable women uncertain of their own position to feel more secure. Supporting a healthy identity involved finding healthy role models and acceptance as well women. Support for autonomy/independence included temporary help in role fulfilment and support in treatment decision making. (Women usually involved their partners in cosmetic surgery decisions). To overcome the stigma of having breast cancer, respondents described companionship of peers and network members and acceptance as 'normal' as being important. Support for women's sexual identity involved their partners' affirmation. Affirmation from friends and peers was also important. Respondents needed to be assured of the love of those closest to them. They received 'expressions of concern' which strengthened bonds and reassured them that relationships were intact.

Chapter Five

Social Construction of Support and Identity Maintenance

This chapter explores positive and negative changes in respondents' relationships since the breast cancer diagnosis and effects of these changes on their perceptions of support/strain. It describes how respondents construct support to maintain or make changes to their identities.

1 Social Networks, identity maintenance and change

Social networks are personal communities and according to Pearlin (1985) they define;

... the outer boundaries of support upon which an individual can draw. ... Whereas knowledge of networks informs researchers which supports individuals can potentially call upon, individuals' active social relations represent the supports to which they are likely to turn. p. 44-45

However, Gottlieb (1985) maintained that;

People do not participate in social orbits which communicate exclusively positive feedback. p. 9

Within social networks, individuals experience their relationships as a mixture of support and strain. Even close relationships are sometimes strained and some relationships are more stressful than supportive. Social support is reciprocal, set within a system of roles and mutual responsibilities. Patterns of support expectations are built up over time. However, people's social networks are not always capable of rendering support in crisis. Network members may be inexperienced in coping with the crisis. Sick people may need support from professionals and others who have been through similar crises and understand how they are feeling. Network members may be unsupportive because their own needs are more pressing or because they feel personally threatened by the crisis. Writers have noted that irrational fears about cancer are widespread. In crisis therefore, people may seek new sources and types of support to complement what is

provided by existing network members or in extreme circumstances they may have to weave entirely new networks.

2 Identity maintenance/change-network members' positive behavioural changes

I have defined support as giving attention to a person to maintain identity rather than requiring attention from him/her. In giving effective support, helpers subjugate their own needs to those needing support. For example, family members spend more time with the sick person. Children help with household chores. People with whom the sick person had little contact before the illness, reactivate ties.

Table 6 shows positive/supportive behavioural changes among respondents' network members after the breast cancer diagnosis and the relationships offering support.

Table 6; Relationships offering support and types of support

Type of relationship	Emotional support	Spending more time with	Practical help	Confiding	Experiential support	Support for sexual identity	Companionship/ advocacy	Totals
Husband/partner	20 (28%)	3 (4%)	15 (21%)	13 (18%)		12 (17%)	9 (12%)	72 (100%)
n=25	11%	4%	25%	46%		92%	70%	
Daughter	12 (44%)	6 (22%)	8 (30%)	1 (4%)				27 (100%)
n=20	7%	8%	13%	4%				
Son	18 (53%)	6 (18%)	9 (26%)				1 (3%)	34 (100%)
n=24	10%	8%	15%				8%	
Mother	9 (32%)	5 (18%)	7 (25%)	4 (14%)	3 (11%)			28 (100%)
n=15	5%	6.5%	12%	14%	13%			
Father	3 (100%)							3 (100%)
n=6	2%							
Sister	13 (52%)	6 (24%)	4 (16%)		2 (8%)			25 (100%)
n=23	8%	8%	7%		9%			
Brother	7 (58%)	5 (42%)						12 (100%)
n=10	4%	6.5%						
Other relatives	18 (47%)	11 (29%)	4 (11%)		3 (8%)		2 (5%)	38 (100%)
n=21	10%	14%	7%		13%		17%	
Friends	34 (40%)	28 (33%)	2 (2%)	10 (12%)	10 (12%)	1 (1%)		85 (100%)
n=35	19%	37%	3%	36%	43%	8%		
Work Colleagues	22 (73%)	2 (7%)	1 (3%)		5 (17%)			30 (100%)
n=23	13%	3%	2%		22%			
Neighbours	20 (59%)	4 (12%)	10 (29%)					34 (100%)
n=25	11%	5%	16%					
Totals*	176 (100%)	76 (100%)	60 (100%)	28 (100%)	23 (100%)	13 (100%)	12 (100%)	389

In each cell, the top figure is the number of patients' comments for that category.
Reading across the table, in each cell, the middle figures are the percentages of various types of support offered by each type of relationship with the patient.
Reading down the table, in each cell, the bottom figures are the percentages of people in various relationships with the patients offering each type of support.

2a Types of identity support

Respondents' identities were maintained/changed by different types of support from network members.

Emotional support

This was the most frequently reported positive behavioural change. Network members expressed their concern for respondents, thus affirming their relationships with them.

Companionship

Network members spent more time with respondents since their diagnosis, expressing solidarity with them and making them feel less isolated.

Practical help

Network members gave respondents practical support with tasks they found difficult to perform because of treatment effects.

Confiding

Many respondents confided their anxieties about their illness/treatment to network members.

Experiential support

Many women received experiential support from friends or relatives who had had breast cancer and from fellow patients.

Sexual identity support

Partners offered important support for respondents' sexual identities, threatened by breast cancer and surgery.

Other support

Other less frequently mentioned but important types of support were advocacy/companionship and treatment decision making.

2b Sources of identity support

Relatives provided most of all types of support excepting experiential support, much of which was provided by peers, friends and work colleagues. Friends, work colleagues and neighbours gave respondents emotional support and companionship, supplementing family provisions in this respect. Most practical support was provided by relatives but neighbours had some input here, proximity making them aware of the needs and availability making it easy to give such help.

Most patients with partners (84%), found these to be their main support. Where women's husbands were not supportive (4), they sought their support from a sister, sons and a close friend. Widowed women (6) found their major supports in daughters (3), sisters (2), a cousin and a niece (1), a daughter and neighbour (1). JW described her neighbours as;

'like a mother and father to me.'

Main supports for three divorced/separated women were daughters, sons, and friends. There was only one single woman whose main support was her mother.

2bi Partners

Partners offered emotional, practical and sexual identity support and acted as confidants. This finding agrees with other research. Ervin (1973) and Grandstaff (1976) found that husbands were pivotal sources of support for women with breast cancer. Peters-Golden (1982) found that husbands' inability to be supportive resulted in most distress for these patients and conversely, those with supportive husbands reported better adjustments to their situation. Some research has shown that disturbed sexual relationships were common following breast cancer (Andersen and Hacker, 1983). However, Taylor *et al.* (1985) found that in most cases, sexual and affectional functioning did not deteriorate significantly after breast cancer, but when it did (more often after mastectomy than after lumpectomy) the marital relationship suffered as well.

2bii Sons

Of 24 sons, 18 were reported by respondents to have been supportive since their diagnosis, two being still at school. Sons offered their mothers emotional support and almost as much practical help at home as did daughters. For 5 women, their

sons were their main sources of support. None of these had the support of a husband, two being divorced, one widowed and two having unsupportive husbands.

2biii Brothers

Of 10 brothers, seven were reported to have been supportive, providing emotional support and spending extra time with respondents.

2biv Fathers

Of six fathers, three were supportive, showing concern for respondents, during their illness.

2bv Mothers

Of 15 mothers, nine were reported by respondents to have been supportive, offering emotional support and practical help including child care. Four mothers became their daughters confidants after diagnosis. Three had recovered from breast cancer and provided positive role models for their daughters. MB's mother was her main support after diagnosis, her relationship with her boyfriend being unstable. Lichtman (1982) explored the mother-daughter relationship in a sample of 78 patients with breast cancer and found that it showed similar patterns to other close relationships which stayed the same or improved. Deterioration in the mother-daughter relationship was associated with maladjustment.

2bvi Daughters

Of twenty daughters, twelve were reported by respondents as supportive to them after their diagnosis. Daughters offered their mothers emotional support, practical help and companionship. For 5 women, four of whom were widows, daughters were main sources of support.

2bvii Sisters

Of 23 sisters, 13 were reported to have offered emotional support and spent extra time with respondents. Two stayed with their sisters on discharge from hospital. For the latter, one a widow, the other having a sick husband, sisters were their main support.

2bviii Children

Children provided some respondents with an interest and purpose in life. JL took pleasure in watching her granddaughter grow up.

The baby was born the day after I had this big operation. I think that's what pulled me through, because it was a granddaughter. The other two were boys. I was determined to see this little granddaughter of mine. I've had four and a half years of her so I'm glad of that. That's been a great life saver. It gives you an added interest in life.

2bix Other relatives

Of 21 more distant relatives mentioned by respondents, 18 offered emotional support, and extra time with them. Four offered practical help and three, experiential support, having recovered from breast cancer. DW's cousin and niece were her main sources of support after diagnosis, taking her to stay with them on hospital discharge, establishing her back in her own home once she began to recover and finally taking her on holiday with them. CG, an elderly spinster, had good support from her nephew.

He phones every morning in life, 'Well Aunt Cathy, how are you this morning?' He comes over a lot because he has an allotment and he often has vegetables for me, Tomorrow morning he'll be here at 9 o'clock and we go to Low's for my messages. B is marvellous. His mother has dementia and she's in hospital. He visits her three times a week. He's got that kindness. He's always ready to help.

2bx Friends

All except one respondent had friends who provided emotional support, companionship and shared interests. Ten women reported confiding their anxieties about breast cancer to friends and ten women knew friends who had recovered from breast cancer and acted as role models. For three women, friends were major sources of support. Two of these women felt unable to confide their anxieties to their husbands, while the third was divorced. EA found her family supportive but did not want to overburden them with her worries. She confided mostly in a friend.

I can talk to them (family) but you don't want to over speak about it. Sometimes you can relate to friends easier than to relations because you don't want to worry your relations. I've known this friend for over 20 years and she had her leg amputated last Wednesday. At the time when I told her I'd discovered this, she said she knew of two people who had been though exactly the same thing and she wanted to put me in touch with them.

In other research, most friendships appeared to remain supportive, although instances of rejection or withdrawal did occur. Lichtman (1982) found that several women shared concerns about their cancer with a close friend that they did not share with their family members.

2bxi Neighbours

Most respondents received support from neighbours after their diagnosis. GC's comment is typical.

I have a very good neighbour, Mrs C. The second time I took one of these turns (colic) I phoned her and said, 'Oh M, could you come down a minute.' I was absolutely doubled in two. She said she thought it was the gall bladder because she had a gall bladder operation and she had gone through all this herself.

2bxii Work colleagues

In all except one case, work colleagues were supportive. JM was a catering manageress.

One of the director's wives had a mastectomy done last year. I've been very fortunate. I've had a lot of good counselling from people I work with.

With advanced breast cancer, AF sometimes found work a struggle. However, her manager had told her not to worry about her job and her supervisor phoned to see how she was. My findings agree with those of Waxler-Morrison *et al.* (1991) who found that working women with breast cancer often became the centre of a large network of information and support. Women tended to work with other women in offices, hospitals and stores. Their colleagues found out and provided information about coping with breast cancer either from personal experience or knowledge of others who had been through a similar experience.

2bxiii Pets

An interesting footnote to sources of support was the inclusion in AH's and SM's network diagrams of their pets, a dog, and a cat and dog respectively. Vines (1993) noted the 'secret power of pets' to provide a special kind of emotional support which is uncommon in relationships between people. Animals muteness can be a boon, not a burden.

Pets listen and seem to understand, but do not question or evaluate. ... It resembles the relationships some psychotherapists try to build. p. 33

Both AH and SM experienced considerable stress after diagnosis. AH had difficulty in persuading her family to give her the support she needed. SM suffered from extreme anxiety and panic attacks. Pets may have been particularly supportive in these instances.

3 Stress; network members' negative attitude and behavioural changes

I defined stress as negative behavioural changes requiring attention from rather than giving attention to respondents. Table 7 shows network members' negative behaviour changes since respondents' diagnoses.

Table 7 Relationships giving stress and types of negative behaviour

Type of relationship	Network member				Total*
	requiring attention from patient.	not recognising/legitimizing patient's sick role.	over-protective towards patient.	undermining patient's identity.	
Sister	5	1	3		9
Daughter	4	1			5
Friends	1	2	1	2	6
Neighbours	4		1		5
Son	3	1			4
Mother	2		1		3
Husband	1	1	1		3
Brother	1	1			2
Other relatives		2			2
Work colleagues		2			2
Father	1				1
Total of patients' comments	22	11	7	2	42
	100%	100%	100%	100%	

*Total of Patients' comments on negative behaviour changes in each relationship

3a Types of stress

Most negative behaviour changes resulted from network members being unable to cope with respondents' illness because of a perceived threat to their own identities. Breast cancer poses a threat to families' as well as to patients' futures, yet members often receive less information and support from professional sources than do patients, although their anxiety may be almost as great. They may react negatively to disruptions in family routines and the threatened expectations that family members hold for one another as members of an interdependent system.

3ai Network member requiring attention from the patient

More female (16) than male network members (6) appeared to perceive breast cancer as an identity threat. This was especially true of sisters (5), and female neighbours and friends (5). With advanced disease, CB reported that her mother, sisters and brother were unwilling to talk to her about her illness because they could not cope. Being separated from her husband, she wanted to share her worries about herself and her teenage sons' future. She was unable to do this.

My mother sisters and brother don't seem to have much time for me. I don't think they can actually cope with it. They just don't talk about it.

MM's sister worried about developing breast cancer herself.

My sister was devastated. I saw her looking at me once or twice. I said, 'You don't think this will happen to you, Ina, do you? It never happened to mum.' She said, 'No but a lot of times it can.' I could see it in her face, wondering if its going to happen to her. It's perfectly natural.

MW's sister was very upset about the implications of the breast cancer diagnosis for herself.

My sister was very, very upset. I think maybe it frightened her to the extent 'Will it happen to me?' There's no convincing her at the moment that it's not hereditary.

EM's sister seemed unable to cope with illness in general and had avoiding talking to EM about her breast cancer.

My sister doesn't seem interested. She never asks how I'm feeling. When she phones she says, 'How is everyone?' She didn't show much interest in seeing my scar. Even when I told her the diagnosis, she said, 'Are you sure?' She's never put her arm round me and given me a cuddle. She had the same reaction to my problem with my knee.

Their mothers' illness seemed to threaten the security of four school age daughters who were unaccustomed to their mother looking so vulnerable. AH's 12 year old daughter wanted reassurance that mother could still care for her.

E's view of it is that, as she said to me when I'd had the biopsy, 'Are you going to be able to take me for my skirt on Friday?' It's her new school skirt. I think that's where it is for her and I was fine to take her on Friday. We went and got her skirt and as far as she's concerned I'm ok again now.

However, when AH later became depressed after breast surgery, E was unable to cope.

I was very down at that time. I suddenly felt very vulnerable physically. The youngest one, she's quite a card really. She rang up her big sister and said something like, 'Mother's in a state. Can I come and stay?' She took herself off to stay with her big sister. She arranged to go for the weekend.

MW's school age daughter developed behaviour problems at school. These seemed to be associated with her mother's illness.

Then we had it last week from P, 'Why my mum? Why has it happened to you?' I thought, 'Oh God, now I've got to start telling schools.' I thought, 'If she's flipped at home, she could well flip at school.' P threw a dizzy at school. She went off the rails. She really did poor lass.

SM's daughter also demonstrated behaviour problems at school which seemed related to her mother's illness. SM visited the school to explain the situation to the head.

My daughter was very upset. I had to go to her school because she was truanting and she was fainting.

Three sons seemed unable to cope with their mothers' vulnerability after their breast cancer diagnosis. HM's son, aged 15, had also to cope with his father's illness (subarachnoid haemorrhage).

He went away, when I was in hospital, to stay with my cousin who he's very fond of because he couldn't hack it any more he said. I know it's certainly affected his school work. He's lost a lot of self confidence but the school is aware of why.

Her 17 year old son coped better.

My 17 year old son seems to have coped best. He was much more emotional about it at the time. He was very snappy and bad tempered. He used to get physically sick when he went to visit my husband.

MW told the health visitor that her 10 year old son had become 'clingy' and attention seeking. SL's son, a university student living at home, was upset by her diagnosis.

I remember when my son and my husband heard the news that I had cancer, they were very upset. My son particularly was very upset because he thought he wouldn't be able to concentrate on his studies. He cried aloud, my husband cried aloud. We were all very tense.

AD's children, aged four and three, initially coped well with mother's illness. However, during my interview with AD, the boy, C, interrupted several times with questions reflecting his anxiety about his mother.

AD My aunt died of breast cancer and my mum went with her when she got the news.

C Excuse me, Mum what happened to your Mum?

AD C, it's nothing for you to worry about, okay.

C What happened to your mum?

AD Nothing happened to my Mum. It's just when Mummy wasn't well and Mummy had to go into hospital, Granny came with me.

The little boy's work at nursery school was affected by his mother's illness as AD discovered after her discharge from hospital.

At the time they were good. They just accepted it. They go to nursery anyway. They came to visit me and they came away from the hospital without tears. Then when I came out and went to work and I went to the school, the teacher said to me that she saw a big difference in C now that everything was now back to normal. It was actually affecting his work. When I came back the second time from the hospital he said, 'Are you going to have to go away again mummy?' It's hard for them. I did explain to them and they were quite matter of fact about my hair falling out. When my hair started to grow in M liked to take off my scarf and stroke my hair. I remember C saying about two ladies who were talking about their hair styles. He said to the other children, 'My mummy is better than that. My mummy takes her hair off at night!'

My findings support those of Lichtman *et al.* (1985) who found that a minority (12%) of their respondents with breast cancer reported deterioration in one or more of their relationships with their children. Problems with daughters occurred more frequently than problems with sons. Mothers of pre-adolescent daughters most commonly reported that these had become extremely fretful over their health and possible death. Mothers of adolescent daughters reported the most dramatic and rejecting responses, with several daughters moving out of the house. The more rare problematic reactions of sons were similar to those of pre-adolescent daughters.

Respondents' mothers were generally supportive. However, PK was hurt because her mother did not visit her in hospital.

My mum didn't come to visit me when I was in hospital. I don't know why. Perhaps she couldn't cope. She doesn't keep awfully well. She's had heart attacks and strokes. She phoned the hospital every day.

Husbands/partners were usually supportive but a few were unable to cope. AB's husband's denial of the seriousness of her illness supported his own position rather than hers.

He kept saying, 'Don't worry', at each stage along the line. I mean he's had it discussed with him all along. I didn't expect anything else, any other result. He just wished it wasn't happening.

MW's husband expressed anger about her illness. Both had been ill and had suffered bereavements in the previous two years and he saw her illness as another assault on his own well-being. However, this mood passed fairly quickly and he became more supportive.

He was brilliant until a couple of days ago when it was, 'Why my wife? Why has it happened to you?' He got very angry but he did go and see our GP. He admitted to me that he felt he had gone through that much in the last two years.

HM's husband was frightened of illness and it was her sister that she turned to for support.

My husband is frightened of anything like that. He doesn't mind visiting you in the hospital but he doesn't want to know the details. It was my sister who went back and forward with me. My husband can't stand the sight of blood.

Six friends behaved negatively. MW's acquaintance seemed threatened by her breast cancer and surgery.

Another woman I know was round for a cup of coffee and my friend said, 'What's it (mastectomy) like Margaret?' This other woman just stood and looked at me. My friend said, 'That's really good Margaret.' This woman said, 'I don't know how you can do that.' She said, 'Oh no' and she walked out. She didn't even stay for a coffee. She actually said to two other women, 'I couldn't let people know.'

JH found that some friends seemed afraid to speak to her since her diagnosis.

With two particular friends, it's as if they are afraid to say anything to me. I think it's a thing that scares the living daylights out of women. Maybe they think, 'There but for the grace of God ...'. One or two friends phoned me up before I went in and believe it or not, I was consoling them on the phone. I think both of them were upset because they had lost their mothers with breast cancer.

Four female neighbours seemed unable to cope with respondents' cancer diagnosis. MS did not want to discuss her recurrence with many people, remembering a neighbour's reaction when she was first diagnosed with breast cancer.

Last time after I'd got better, I was at the bus stop and there was one woman who kept looking at me as if she expected me to drop dead at any minute. I've always remembered that and this time I did want to keep it quiet.

AB's neighbour had had breast surgery herself and seemed to find A's breast cancer threatening.

I find my neighbour 'trying'. She enquires every time I go up the road if I'm still alright. My neighbour has been in the Breast Unit herself. She had some minor operation, so she looks at me with an expectant eye.

MM resented her neighbour's attitude to her breast surgery.

My neighbour said, "Did you have your breast off? Oh dear!" Thank God I'm not at the weepy stage. That would have been all you needed. It's not a thing I've discussed with a lot of people.

3a ii Network members not recognising /legitimizing patients' sick role

Some network members (11) did not recognise/legitimate respondents' illness and so did not give them the support they expected. They seemed unwilling to accept that respondents were unable to fulfil their normal roles. This threatened their own accepted roles and identities. AH was very depressed following breast surgery and felt that her husband and children made light of it, not acknowledging her feelings.

That was also part of my being a bit down. Everyone was coping very well with it, but it was very much, 'Well you're okay now aren't you?' I was sort of thinking, 'Well yes I am but no I'm not.' It was a case of having to be okay. I broke my ankle a couple of times in the past. Everybody (family) thought it was a great joke. It gave them lots of scope for facetiousness. Then there was an end in sight, while this is a bit more indeterminate. I think they are a bit uncertain at the minute what it is. They've been saying things like, 'You're not back at work yet. You're just skiving.' When you are feeling low you need a bit of understanding, don't you? It was quite hard because it wasn't until I was really quite down that they sort of acknowledged that I was feeling low. I had to shout quite loudly about it. In fact Ben (husband) has always been very busy and he was rushing around a lot. He was perhaps the last one to notice.

There were four instances where longstanding relationship difficulties might have accounted for lack of support from some network members. However, sick people expect allowances to be made for their incapacity. Respondents were disappointed

when this did not happen. With advanced cancer, AF , found her son and daughter unhelpful at home. Family relationships had been difficult for some time.

They will not wash a dish. They won't do anything for you. With F it's just a recent thing. It didn't get really bad until she started going with S. K's always been like that.

JN had always had a difficult relationship with her sister but resented her apparent unconcern about her illness.

There's no love lost between us. My sister only visited me for 2 hours after my mastectomy although she was staying in Paisley for a week.

JL had longstanding problems with her adopted daughter, J. She was disappointed that J did not visit her more often during her illness and continued to demand money.

J's got a new boyfriend and she doesn't come to see me very often now. She did come and stay for a week with the baby, but it was too much for me. The bairn was driving me daft screaming. J tries to take charge when she's at home. She was adopted when she was five. She was emotionally disturbed. J is always wanting money but the money is not there to help her. She's more well off than I am now. She's a worry to me.

PY was upset that her daughter now seemed more concerned about meeting her new boyfriend than supporting her.

Since she met this boyfriend, she's a completely changed person. She'll just come in and get herself ready and can't get away quick enough.

EC experienced negative behaviour from four of her network members who seemed more concerned with their own needs than with hers. She felt, for example, that her brother had not been supportive having 'only phoned twice'. She also had two aunts in Holland, one of whom was upset because she had been expecting to come and stay with EC.

She phones me up every day. She really only thinks of herself. I've been told there's one person I've got to look after now and that's me.

With advanced breast cancer, CB found her work tiring while having chemotherapy. Her work supervisor showed little understanding of her situation.

I considered leaving. There's only really one woman that I'm up against. When I did get the letter the first time about the hours of work changing I said to my boss, 'Are we not supposed to be asked about this?' She said, 'Look if you go upstairs about it, you'll be out.' That's the way they work. If you don't like it you're out.

3aiii Network members overprotective towards patient

Support needs to be balanced against individuals' needs to perceive themselves as coping. Some respondents reported that network members had been overprotective towards them since their diagnosis. This affected their self esteem and identity as independent people capable of giving as well as receiving support. In a study of adjustment of individuals to heart attack, Johnson (1991) noted that;

If the informants believed they were incapable of reciprocating support, either immediately or in the future, they felt devalued as human beings. As the informants began to improve and gain strength in the immediate weeks following their discharge, their need for support diminished. If their family members were not cognisant of their improvements and continued to provide support in the same ways, without modification, the informants felt over protected.

Three sisters had behaved overprotectively towards my respondents. AB's sister had previously had breast cancer. Her overprotective behaviour was preventing AB's return to normality.

My sister is the one who fusses most which is understandable probably but I found I could do without it. I appreciate her concern but if somebody tells me too often to take it easy, my reaction is to do the opposite. I appreciate her efforts to keep me in check but I feel back to normal now.

AC's sister had not told her about her own breast lump biopsy three years previously.

I told my sister before I knew what the lump was. She said, 'Oh, I had that two or three years ago'. I didn't even know about it but hers had been fluid. She was convinced mine was fluid. She said, ' Don't worry about it. They'll just drain the fluid off.' She had gone through that and she hadn't said anything. Because I'm the baby of the family, even though I'm 53, my sisters still tend to protect me.

EH felt that her family members were overprotective.

They're all terribly uptight and worrying. My mum would be on the phone saying, 'Now what was the results?' My sisters, my son, and my eldest daughter had it all arranged. They were all taking weeks off their work so that they were all going to be here for a week. I thought, 'This is going to drive me round the twist.' They all think I should just sit around but it's not my nature.

3aiv Network members undermining patient's identity

In two instances network members undermined patients' identities. With advanced breast cancer, AF did not want people to know about her illness and was upset when a friend broke this confidence.

M spoiled things. She said, 'It's all right. M knows about you but she'll not say anything.' She'd no right to tell anybody. She was told in confidence.

EC who had inoperable breast cancer, was already very anxious about her prognosis when a 'friend' who belonged to a religious sect phoned to enquire about her health and asked her if she was 'ready to die'.

4 Network members' behaviour unchanged since breast cancer diagnosis

Thirteen respondents reported that one or more of their network members had shown no significant changes in their behaviour towards them since their breast cancer was diagnosed. Respondents reported that some (8) network members were unable to support them because of illness and needing support for themselves. Three women felt unable to discuss their anxieties with their sick husbands, wishing to protect them. HM's husband was recovering from a subarachnoid haemorrhage.

He came out of hospital after four weeks which was just about the time I was getting my results (staging for breast cancer). The Unit allowed me home during the day, once I'd only got one drain in. I was here when my son came home from school. I'd remind my husband to take his pills. I think it helped my just being physically around. At the time I was in the hospital, he got quite spaced out. I would say he's come to a plateau now and he's about 80%-85%.

EC's husband was a heavy drinker and she worried about his health.

I try not to say too much to my husband. I'm always worrying about him because he does get tired. It's really me that's been keeping everybody going and now here's his mainstay suddenly-well I think he thought I could carry on for ever.

SS felt she had to protect her husband from worries which might exacerbate his psoriasis. EL's mother seemed to be preoccupied with her own illness.

My mother has Parkinson's disease. She is always talking about wheelchairs. She has good days and bad days and she doesn't see any future.

MM's mother had senile dementia and did not understand that her daughter had been ill. In four cases, network members seemed unable to offer respondents support because they were preoccupied with their own problems. For example, PY had a son who had a drink and drugs problem and had been sent to prison. His negative behaviour did not change when she became ill.

5 Reciprocating support

Several writers have described social support as an interactional exchange of resources, modelling it on exchange principles. Cobb (1976) defined support as a network of mutual obligations, and spoke of a norm of reciprocity. Is this norm of reciprocity maintained during illness? In a study of young patients with cancer, Lynam (1990) noted that supportive relationships were reciprocal. Each party in the interaction played a part in maintaining it. Many of her respondents took responsibility for educating people around them about their illness and helping them to understand how they could be supportive. Being able to participate evenly in interactions was important to her respondents but their ongoing vulnerability compromised their ability to do this.

5a 'Normality' not 'equality' in roles and relationships

Respondents spoke about their increased feelings of vulnerability and powerlessness. For example, women whose sexual identity was threatened by breast cancer depended on their partners to restore their self esteem. Women with young children were less able to provide security for them because of feeling vulnerable themselves. Many women expressed a desire to be less dependent on others for support and to 'get back to normal'. However, 'getting back to normal' did not necessarily mean participating more evenly in supportive interactions with others. It often meant restoring relationships and roles to what they had been before the illness. They were not always egalitarian, but they were the relationships and roles in which individual identities were embedded and maintained. For example, JM was anxious to put her illness behind her and to return to her normal family and work roles.

I'm just dying to get on with my life. I just want to put it behind me of course. The day I was out of hospital, I was washing the floor in the kitchen. It was stupid. My husband and my son were really angry. I realised myself it was stupid because the next day I was absolutely shattered.

Former relationships did not always involve evenness in participation. In their relationships with their children, women saw themselves as providing security, love, protection, while they expected the children to respond in a way appropriate to their ages. Young children were expected to respond initially, only with demonstrations of affection which affirmed women's identities as good mothers or

grandmothers. EH's 3 year old grandson lived with her. She found him very affectionate. Her other grandson visited her frequently.

I can't imagine him not being here. He just makes your day with his wee expressions. A lot of people think he's a lot of work but he's not. He's such a good wee boy. He just potters about and keeps kissing my arm thinking that will make it better. He gets upset if I'm late coming back from the hospital (radiotherapy). I think he thinks I'm not coming back. They make you laugh some of the things they do and some of the things they say. They keep you going. They bring a lot of joy into your life. It helps a lot.

Respondents' perceptions of being well supported depended on whether their identities were maintained by their various relationships rather than whether they were receiving as much support as they gave. EH (above) enjoyed her work as a home help and was anxious to resume it as soon as possible.

I can't wait. I really want to be back at work, to be into a routine because I find that over this busy time, it's fine, but after Christmas, time is going to hang about.

JN identified with her WRVS work and wanted to return as quickly as possible.

I do the WRVS three days a week. The stock keeper and I see to it that there's plenty of cash for the change. I enjoy it. I don't know what I'd have done if I didn't have it. I'd have had to have done something.

Oakley (1974) and other feminist writers have shown that the housewife role was important to women's identities, although husbands did not participate evenly in household tasks. She administered a test of 'self attitudes' to 40 respondents and found that 25 of the women mentioned 'I am a housewife' at some point in the test, most doing so early. In an overview of contemporary marriage research, Clark and Haldane (1990) maintained that there are still visible differences and inequalities in male and female experiences of marriage.

Men frequently experience and see marriage as something that supports them in the world of work, providing domestic back-up which makes their working lives easier. ... By contrast, when women get married they are likely to experience immediate tensions between the demands of paid work outside and their unpaid labours inside the home. These will not only be pressures of time and physical energy. Housework and cooking are also 'moral categories' which 'say something' about a woman's feelings for her husband and their marriage and which communicate to significant others such as parents and siblings and friends. p. 27

MM had been re-admitted for further surgery after her local tumour excision. She expected a rapid return to her role as homemaker after her discharge from hospital.

When I first came out of hospital, my husband was good then in practical ways.
Of course I do it all now.

However, in relationships with their peers women saw themselves as supporting each other more or less evenly.

5b Ways of reciprocating support

I found that respondents' desire to reciprocate support from their network members was seen in three ways;

- a early resumption of normal roles
- b protection of network members from stress
- c offering to support to others

5bi Early resumption of normal roles

In families there are often mutual expectations of support and responsibility which are difficult to adapt in illness. Robinson (1992) noted that some families adjusted better to the illness of a member than did others. These were families where there was flexibility in and between roles and where there was direct and consistent communication and tolerance of individualism. My respondents spoke not only of their network members' expectations that normal life would be restored after their recovery but of their own anxiety to 'get back to normal' as quickly as possible. In this way, family members protected each others identities.

Patients' expectations

AB's sister felt that A was doing too much at home after her recent discharge from hospital. Although her husband had taken time off work, A was used to doing things for him. However, AB was most anxious to resume her normal roles including caring for her elderly mother.

I used to have regular afternoons when I went up there (mother's house), plus quite a lot of visits, but my sister won't let me take on any regular afternoons. We have people coming in but it's more expensive. Also my mother prefers it if one of us is there because otherwise she feels she's being a nuisance and having to be taken care of.

AC was anxious to reciprocate her friends' kindness during her illness.

The first four weeks I was very, very tired and I had no energy but since then I've done decorating here. I've done decorating for my friend down the road. I've

helped a friend down in Durham. It's just been all go and I've thoroughly enjoyed it.

Many respondents were grateful for the support they had received from work bosses and work mates while they were ill and were anxious to get back to work as soon as possible in return. HM went back to work sooner than she had intended to help them out.

There comes a point when it doesn't really do any good to sit at home. There's also the fact that you need to move up into the next gear or else you can wander round feeling sorry for yourself for ages. I think it's good to get back to feeling reasonably normal.

MP was anxious to return to work because her clients had shown her consideration when she was ill.

My jobs (cleaning) are good because I hardly ever see my clients but they've been very kind to me anyway in saying, 'You be careful and do what you can.' So I just do dusting and that.

EM had done domestic work for the same family for many years and found her employer very supportive when she was ill. She felt a moral pressure to return to work as quickly as possible to reciprocate this kindness.

She phoned just to check how I was. Normally I'd have been there to get the dinner into the Aga. I really felt like saying, 'Hold on and I'll be there in a couple of minutes', but at that point I didn't feel I could, so I waited until the end of January. I've been back four or five weeks but it's been pretty tiring.

Network members' expectations

Network members also expected resumption of normal life once the patient had recovered. Many respondents had received help with housework from their family members but this role change for husbands and adult children often seemed temporary. PK's husband and son apparently expected to return to former patterns of family life. This seemed to be her wish too.

My husband and son help with the housework because my arm movements are still restricted. Mind you I'm not mollycoddled. When I'm at home, it's 'Mum's home.' Really it's the best way. I'm getting on with it. I can do it. If I'm having difficulties, I just have to say, 'Would you ?' and they will.

HM felt great pressure to make a quick recovery from mastectomy as her sons and daughter were caring for their father who was ill.

One had so many external pressures to recover and get home because it was hard on teenage kids to have to look after him at that time. Until my sister came, the kids had quite a difficult time.

However, two patients resented the expectation that they would resume their normal family roles before they were ready to do so.

I had an argument with the oldest one (daughter) last night. She's complaining because her trousers aren't ready for work. She's been on holiday. I said, 'You've been off all week. You could have seen to it yourself.' She expects me to do it. EL

AH was initially anxious to take up her normal household duties, but later became depressed because she had not received the support and understanding she expected from her family. She resented their treatment of her as someone who was not really ill.

I was very down at that time. I think it was all sorts of things but I think it was mainly around that I'd been very active and very positive wanting to get back to being physically okay, determined to do everything.

5bii Protecting network members from stress

One way in which respondents sought to protect the identities of their network members was in shielding them from anxiety about their breast cancer. Some women were reluctant to confide their deepest fears to their family members even when the latter were quite supportive because they wanted to protect them from stress. Eve C's husband offered support but she felt that she couldn't talk to him about her fears.

It seems odd that you can't confide your worst fears to your nearest and dearest but it doesn't work that way really, especially when it's something you think is so final, like your imminent demise. You can't say that to your partner. You're just going to upset them.

Eve C adopted the same protective attitude towards her adult son who was living away from home, not telling him about her illness until she was well on the road to recovery.

It's hard to share with your family because you can't put it all onto them. You're protecting them. My son doesn't know about it. I haven't told him. I didn't see the point in just quickly telling him bad news. When you are feeling better, the tone of your letter will not be so miserable and more positive. You can say you're on the mend rather than saying you are having this operation for cancer. It sounds so dire.

MS also wanted to protect her husband and family from the bad news of her breast cancer recurrence.

I didn't even tell my husband until it was about two days after I'd been to the doctor. I just didn't want to disrupt his life and the children's life. I felt that if he had come to clinics all the time, his life would have been really disrupted. It's important to me that the family's life is not disrupted.

SS felt the need to protect her husband from any stress connected with her illness, as he had psoriasis.

My husband has never spoken to any of the doctors. The only thing I did say to M (counsellor) was that I would have to watch him, keep things on a calm level because my husband has psoriasis. It's shocks to the system that can bring it out.

SL felt very depressed but did not share her feelings with her family because she thought this might affect their future relationships.

You don't want to worry them. You've got to live with them when you are alright as well.

MH saw quite a lot of her daughter and grandson who lived in Edinburgh, but did *not* worry them with her anxieties about her prognosis.

They have their own lives to lead. You can't live through other people.

EC was her husband's main support and she protected him from worry about her breast cancer. He had a drink problem.

I try not to say too much to my husband. I've been worrying all these years that he would get liver cancer. Little did I think it would come to myself. I'm always worrying about him because he does get tired.

Protective behaviour of mothers towards their children was to be expected. Nevertheless, some women took great care to protect their children's sense of security. CB with advanced cancer, worried about the future of her two sons, aged 15 and 16, after her death. She rarely discussed her cancer with them. MM did not want to upset her sons, aged twelve and ten or her elderly mother by telling them much about her breast cancer.

We didn't go into great detail about it. I didn't really want to upset them because they've continued quite naturally. I'll tell them again that I'm going in to hospital (for mastectomy). I'll just tell them a couple of days before I go, so that again they are not at all worried. My mum, I don't worry her because she's in a home. I just keep it quiet. She's slightly confused. As far as she is concerned, nothing has happened. That's the way I wanted it with her because I don't want anything to upset her.

AH wanted her young daughter (aged 12) to see her as being fully recovered from her breast cancer.

As far as she's concerned I'm okay now. What I don't want is other people to be talking about it and their kids picking up bits and things coming back. Just at the minute I want her to see me as quite hale and hearty.

5biii Willingness to support others

There were many ways in which respondents offered support others. EA wanted to reciprocate her friend's support now that the latter was ill.

Looking after my friend's children last week helped me a lot. It was thinking about other people. My mother says 'You shouldn't overdo it', but I wasn't doing very much at all. I was just giving a bit of moral support to her husband. Doing that does help yourself.

JJ was anxious to return the support her mother had given her when she first came out of hospital.

My mother moved in for about a month but I'm back at work now. She had actually cancelled her holiday which I didn't know about at the time. Her reasoning was 'I couldn't go away while you're going through this.' I felt she needed the break so we bought her the tickets and said, 'Get your cases packed, you're going.' She had a nice three weeks.

Respondents also supported their fellow patients. Women helping each other to overcome the stigma of breast cancer and to return to normal life.

6 The balance of support and strain in social networks

Table 8 shows the balance of support and strain offered by respondents' different relationships. It does not indicate the quality of support given by or the intensity of strain from these relationships.

Table 8; Balance of support and strain offered by different relationships

Relationship	No. showing positive behaviour changes	No. showing negative behaviour changes	No. whose behaviour was unchanged	Total no. for each relationship
Other relatives (e.g. aunts, cousins)	19 (90%)	2 (10%)	Nil	21 (100%)
Husbands/ partners	20 (80%)	3 (12%)	2 (8%)	25 (100%)
Sons	18 (75%)	4 (17%)	2 (8%)	24 (100%)
Brothers	7 (70%)	2 (20%)	1 (10%)	10 (100%)
Mothers	9 (60%)	3 (20%)	3 (20%)	15 (100%)
Daughters	12 (60%)	5 (25%)	3 (15%)	20 (100%)
Sisters	13 (57%)	9 (39%)	1 (4%)	23 (100%)
Fathers	3 (50%)	1 (17%)	2 (33%)	6 (100%)
Total number	99 (70%)	28 (20%)	14 (10%)	141 (100%)

70% of existing relationships offered respondents increased support after their diagnosis, 20% showed negative changes and 10% were unchanged.

In close female-female relationships support seemed more ambivalent than in close male-female relationships. There were more positive behavioural changes in relationships with husbands, sons and brothers, than with sisters, mothers and daughters. Perhaps this reflects the female identity threat of breast cancer. Apart from more distant relatives who were less likely than close family to offer intensive support, partners seemed to offer the most positive support.

6a Supportive networks

In 14 (40%) of social networks, relationships predominantly offered respondents support rather than strain. Relationships among patients' family members in this group seemed good. Network members had no serious illnesses to divert support away from respondents and seemed able to cope with the patients' illness without perceiving it as threatening to themselves or to their position within the network.

One supportive network was that of JM. She lived with her husband and adult son and had a large extended family and many friends, two with mastectomies, living

nearby. JM worked as a catering manageress and her boss and work colleagues were very supportive. She had befriended two fellow patients from the Breast Unit.

I've had great support from my family. My mother is still living and I've got four sisters, all in Edinburgh. Everybody has been very helpful. My daughter lives just round the corner. It must be terrible for people that's on their own.

The extended family met frequently, communications were open, sharing of problems encouraged.

I see them all the time. I've got people round me if I want to speak to anybody about it. My sisters and my mother, we are all very close. If I'm upset, I would just phone one of them.

JM had a close, supportive relationship with her husband. He (and family) helped her decide not to enter the Scottish Breast Cancer Trials but to accept the standard treatment instead. JM had also had a lot of support from her work colleagues and her boss.

I'm a manageress in X's catering. I've had a lot of good counselling from people I work with. One of the directors' wives had a lumpectomy done last year. I got a bouquet of flowers from the Highland Show Society. I'm dying to get back to work.

She had a lot of peer support.

I have two friends who have had mastectomies, so it's all around me, and they are close friends. Along at the golf club, there's two of the wives that have had it. M had a mastectomy in October. I was speaking to her. She's back at the golf club, playing golf. I've been getting confidence from speaking to these people actually. When I was up for the radiotherapy, I met a lot of the women I was in hospital with. Five of us have been out for lunch. There's a couple I'm going to keep in touch with. There's K in Dalgety Bay. When we had our radium implants, K was in the next room to me in the hospital. I went and leaned out of the window and we were talking to one another.

6b Mixed support and strain within social networks

Eighteen networks offered respondents a mixture of support and strain. There were some longstanding relationship difficulties between women and their network members in this group. In a number of instances, another person was ill or unable to cope with the woman's illness, regarding it as in some way threatening to him/herself.

PY's network followed this pattern. Her family were quite 'close' and they saw a lot of each other. Her main source of informal support was her daughter, B who gave her practical and emotional support.

Barbara does the tidying up and the washing. I can talk to her. Last week with this pain, I couldn't sleep and I was crying and the wee one (Barbara) said, 'Mum, I'll get the doctor to come in.' I said, 'No.' I couldn't handle hospitals. I said, 'We'll just see how things go. Will you sit beside me and hold my hand?' I'm feeling low at the moment.'

B's boyfriend', K, and his mother also supported PY. K painted the flat to cheer her up and his mother visited frequently and shared an interest in music with PY. PY also received support from her mother, her sister, her daughter J, her sister in law and her brother B who visited her from Canada. Three friends visited regularly. However, some relationships within PY's network were more stressful than supportive. Her son M had a drink and drugs problem and was currently in prison.

It's the things he does when he gets on the alcohol. He just goes out and starts fighting and stealing from people. He stole my purse three times. He landed in prison. He thinks he should just get his own way and we're here to help him. He forgets what he's done to us. He thinks I should forgive him all this. If M does get out, he'll start taking valium again. I just can't handle him. I've had to call the police and ask them to remove him from the house because he just starts to wreck the house. He's selfish.

There were always multiple problems in PY's family. At the third interview PY was very depressed, suffering from a severe radiotherapy skin reaction and frightened to leave the house. She worried about her mother's angina and her father's senile dementia. Her daughter, L, was pregnant and PY worried that the baby might inherit a disability from L's boyfriend. A sister in law of whom she was very fond, and an aunt, had died. Her son was still in prison and P felt that life was very stressful when he was home. He had started coming home for the day, but was already asking for money from his mother and sisters.

EC also received support and strain from her network members. Her two sons were supportive as were her brother, sister in law and two aunts. E had many friends, several close, one of whom was staying with them. She had church and work friends. On the other hand, she had a brother who had only phoned her twice during her illness. Her husband, J, had a longstanding alcohol problem and suffered from ill health. Protecting her husband was an important aspect of EC's identity. She did not seem to expect any support from him. Her friend (L) tried to persuade EC to confide more in her husband.

- EC I try not to say too much to my husband. I sort of try. I suppose he's coping quite well.
- L I think maybe you should talk more to J about it, otherwise he might begin to feel that you're sort of pushing him out and you only want to talk to me or you only want to talk to C (son).
- EC I don't want to tell him about these various funny pains that I have.
- L When J came in last night, you said, 'Come on J, have your meal and get to bed.' I thought, 'Poor old J. He's only just walked in the door.'
- EC Well he had viral hepatitis two or three years ago and we had a scare last year. He was whisked up to the Royal because they thought he had leukaemia. So I've been worrying all these years that he would get liver cancer. Little did I think it was going to come to myself. He runs a taxi and I feel it's such a stressful job. Some weeks he doesn't make any money at all. He certainly wants to help. On his two days off he says, 'What can I do for you?' He wanted to lay the table.
- L But you wouldn't let him.
- EC I wouldn't let him because that's me not wanting to give in. I want to do as much as I can.
- L You've got to receive help as well as give it.

At the second interview, EC was still trying to protect her husband and was glad of the opportunity to confide in the health visitor.

We discuss him (husband) as well. I've really got to have someone that I can talk to. I don't want him to feel left out. C, our younger son came to the clinic with me. I said to J, 'It's not that I don't want you to come with me but I really think you ought to have a rest because you've been working quite hard.' C is quite prepared. My husband is supportive to a degree that he keeps saying, 'You are going to get better.' I don't know whether that's just him in his mind, hoping that I am.

6c Stressful Networks

One patient, AF, received considerable strain from her informal network, her main support being her health visitor. AF was separated from her husband who did not know about the recurrence of her breast cancer. She had two sons and a daughter. Her married son, A, gave his mother practical and emotional support.

He's the one I'm closest to at the moment. I think this is because he's more worried with not being in the house and just being married.

Her son K and daughter F did not do much to help their mother, although she often felt tired and unwell. AF thought that her illness frightened them, and they did not want to listen to her talking about it.

They still rely on me to do the shopping certainly, the housework certainly and washing and what have you. I mean, Sunday was quite a bad day pain wise.

They can't be any worse the two of them. It's up to me to 'Get on with it. We've heard enough of it.' They just don't want to know. They're scared.

She had only two friends, not close, whom she saw occasionally. It is possible that her illness may have increasingly isolated her from potential support.

I haven't any good friends really. A couple of women I worked with at College come up now and again. We have a game of cards sort of once in a blue moon. No there isn't anybody else.

She did not have much contact with her neighbours.

I've been here since August and they don't speak to you. They tend to congregate and talk about you, so I just let them get on with it.

She did report receiving some understanding from her work boss.

7 Synchrony and discord in perceptions of support needs and support available

Sometimes individuals' and network members' perceptions that a crisis has passed do not coincide and problems occur. Among my respondents, there were examples of this. Two involved denial of the seriousness of patients' illness by their partners and another resulting from a family not perceiving a patient's depression and need for support. JL took over a year to regain the confidence she needed to resume her normal life and to release her husband from his role as her carer.

I couldn't possibly let my husband go back to work and be like I am and on my own all day.

The health visitor attending JL noted,

At times, J's husband has been very stressed by her demands.

Sixteen months after her breast surgery, she was going out every day, travelling on buses without her husband and walking short distances. Her husband, was still very supportive was more relaxed now that J was less anxious.

MW had a long period of treatment prior to breast surgery and postoperatively her recovery was delayed by several complications. It was about a year before she began to feel that she had recovered. This delay in returning to normality caused a discrepancy between her perceived needs for continuing support and the support that was offered by family members and friends.

When I had this (implant) done again, I began to wonder, 'Will I ever get well again? Am I ever going to get to the stage where I'm back working and putting the family back together?' In the last year it's been, 'No, we can't do that. Mum can't do it', or they've gone and done things that we normally would have done together because I just couldn't do it. Also there's a bit of pussyfooting around. People don't invite you out as a couple because they think you are not well enough, or they don't want to discuss it. It's got to the stage with some friends, where I just don't mention it because I'm beginning to feel that they think, 'Oh my God, she's on about it again.' In the beginning, they were very, very interested. A year is a long time to keep that interest going. It's not because they don't care. Also I think some of them are getting to the stage where they're frightened to ask me. When I went back in and had the implant put back in and then had to get it taken out, a couple of friends phoned P (husband) and said, 'Are you sure it's not because there's more cancer there that M is so ill?'

A sick person may wish to resume her normal roles while network members may decide that she is not ready for these responsibilities. JM was anxious to return to normal as quickly as possible and her family had to almost force her to accept support.

8 Changes in network membership since the breast cancer diagnosis

Respondents' and network members' needs to maintain and make changes to their identities after the breast cancer diagnosis often resulted in changes in network membership. Sometimes these were initiated by the women themselves, other times by their network members.

8a Lost relationships

Occasionally, network members lose contact with respondents altogether as a result of *their* own identities being threatened by the illness. MW had this experience.

Funnily enough one friend hasn't spoken to me. Her husband still phones me and asks how I am. I say, 'I'm fine.' I can't understand why she's like that. I've phoned her a couple of times myself and she's very curt. I thought, 'No, I'm not into this. It's not my problem. It's hers.' I was very hurt in the beginning about it. I'm not now.

AC lost the friendship of a neighbour who seemed frightened by her breast cancer.

There's only one neighbour actually who hasn't been so friendly since I've been ill. I think it's frightened her. I think she can't cope, because we were very close. I would have said she was probably the closest friend up here. I saw her a couple of times and then she just sort of withdrew completely. I thought, 'Well there's

nothing I can do about it. If it frightens her then I can't fight her battle for her as well as my own. It's unfortunate, but that's it.'

HM lost contact with a neighbour who seemed threatened by the disease.

I was depressed because two of my neighbours crossed to the other side of the road. I found that one of them had quizzed my husband. After I got over all that I thought, 'Well who needs neighbours?' It's nice to be nice to people but I don't really need them. Before I had this operation, she was in this house four mornings every week. She used to bring her bran scones. She's never been in the house since I came out of hospital. I'm not unduly worried because she's the kind that's frightened off by all this. A lot of people are.

AD lost contact with two friends since they heard about her breast cancer.

There are a couple of people who I have completely lost touch with since they heard, because they just can't deal with it. I suppose everybody is different but I'm not interested in those sort of people. What sort of friends are they, when they can't give you support when you need it?

AC was still receiving treatment for her breast cancer but lost contact with another patient who had finished treatment and wanted to put her illness behind her.

Y used to phone regularly but we've nothing in common now. Y has finished her treatment and she's back at work.

JL had unsuccessfully tried to maintain contact a fellow patient. Her husband, J, felt that such relationships were only transient, 'like meeting people when you are on holiday'.

I phoned R. I got awfully pally with her. I phoned her up when Songs of Praise was on. It was that early. She was a bit stropky on the phone. She said, 'You got me out of bed.' Then she started. I thought, 'Oh well.' She said, 'You can phone me back another time.' I thought, 'To hang with that. I'm not phoning you back.' She was quite snippy, so I threw away her number.

Two of the three patients with advanced cancer no longer had much contact with other patients although they attended hospital clinics. AF's main support was her health visitor, while CB's was her regular visitor from Family Support. Four of the five patients with inoperable cancer did not have peer support. MB and MH attended the Breast Unit clinics but there were few opportunities for sustained contacts with other patients. Neither woman, however, seemed to be seeking peer support. MB had support from her family and boyfriend, and MH who had recently been bereaved of her husband, was not wanting the contact.

Sometimes respondents themselves ended relationships with fellow patients when they felt these threatened their identities as 'well women'. Eve C, a psychiatric nurse, made this decision.

The relief is actually sharing with people who have got the same thing but there's something about prolonging things. I suppose it might have been different if I'd had more radical surgery. I don't feel I need to sit and share again. I think it comes to the bit, even in the type of work I do, when you think, 'Well, that is enough.' You have done the work and now you have got to incorporate it into general living.

SM had had supportive relationships with two patients when in hospital but became frightened to contact them in case they had developed recurrence.

S and E were helpful in the beginning because they were in the same boat. We had a good laugh. I feel guilty about not phoning them, but I don't like to contact them now in case they are not all right.

EC decided she wanted no further contact with a fellow patient who suggested that they both had advanced cancer.

She said, 'I've been looking up a book today and it says *'peau d'orange'* is advanced breast cancer.' I said, 'Well I wonder what that means?' She said, 'I don't know but it doesn't sound very nice.' Well I haven't got in touch with her again. I feel a bit mean in a way because we were only talking over the phone but that wasn't a particularly good form of help.

EC had also had negative contacts with fellow patients in hospital.

When I was in hospital, the lady opposite was on oxygen all the time. However, for a few seconds she took this off and said she had cancer in the lungs and it really was just a matter of time. In another bed was another lady having a blood transfusion. She was quite wonderful but her husband couldn't cope. He used to come in and say, 'Oh darling what am I going to do without you?' She'd say, 'Now look, I've just got a few weeks left and I've got to make the most of it.' When he went out she'd say, 'How am I supposed to cope?' She was wonderful but she knew she hadn't very long to go. Well, it was quite depressing.

At 28, LB wanted contact with someone of her own age with whom to share her concerns about having a family after breast cancer. She was not interested in joining a support group as she felt that the other women would be older. AH did not want to attend a group in which breast cancer might be the sole topic of conversation.

I haven't gone to any of the support groups. I suppose I feel that I just don't want to go to something that is just thinking about that. With these others (friends with mastectomy) we can talk about that but we are also talking about other things.

JB felt that a support group would remind her of her illness.

I always intended to go to the support group but I never did. It's the sort of thing when you feel low you are not able to go and when you are feeling alright you don't want to be reminded. It's the sort of thing you put off I think.

8b New relationships

As a consequence of illness, individuals may seek out or encourage new relationships. These may remain part of their networks after recovery or may terminate when the need that originated them has passed.

8bi Peer support

Contact with peers can provide experiential support, comparison support, and companionship. Respondents developed relationships with fellow patients who were diagnosed at the same time and who underwent three days of investigations (staging) together. A kind of 'crisis bonding' occurred because their minds were in turmoil. It was comforting to know that others shared the same fears.

Perhaps accidentally, the Breast Unit created almost perfect conditions for peer support. Respondents had opportunities to compare their own progress with that of patients who had had surgery at the same time and with those who were about to be discharged home. MW needed several months of pre-surgical treatment for her large tumour. She described the bonding process.

We spent our first three days during our staging sitting there, nails to the knuckles. You are sort of bonded together as a group. By the time you'd trailed off to have an x-ray and trailed off to have a mammogram and all complained, 'Oh my God, it's painful', you were beginning to get friendships. When you have just spent three days with people who were in exactly the same situation as you, you do form friendships and quite strong bonds with each other. When you've been there for three days from eight o'clock in the morning to eight o'clock at night, you do sit and talk. C, the receptionist (clinic) has kept us together. she's made a point that she keeps two appointments together because M comes up from Coldstream. We go to the WRVS and have a coffee.

JH also formed a bond with fellow patients.

I've phoned one of the ladies who was on the staging programme. That was horrendous, the tension. I felt like an elastic band that was ready to snap. You feel, 'Gosh they are looking here, they're looking there. are they expecting to find it in my hand, my feet?' It's such a strain and you're together for three days. You form a bond with these people because you are sitting round the hospital waiting.

Twenty six women (74%) developed peer friendships. Sixteen were at a deeper level not being confined to meetings within the Breast Unit. Women exchanged addresses and phoned each other at home. Some met for coffee or a meal. JJ befriended three patients.

I think something like that helps, bonds women together. There's one girl at Rosyth, one in Penicuik and another in Edinburgh, the three of them. I think I will keep in touch with them.

This friendship was helpful to JC, one of the women in JJ's peer group.

We went through it together J and I, so we're keeping in touch. I had a phone call from J. She had the mastectomy. She had the built up breast. J is doing fine. I said to her, 'I've not got long to go now J, until I'm finished. She said, 'That's great.'

PK felt that her peer group was like a club.

It's almost like a wee club. One girl, Olive, I've become very friendly with. She's coming over for coffee on Monday. She's been having a hard time. She's been in three times to get it sorted out. It's nice keeping up with people. You've got something in common like that and you keep each other going.

Ten women (28%) met fellow patients only at Breast Unit clinics. In four cases, this was because contact with other patients had not always been supportive. Also, talking about their illness made them feel anxious. HM did not want contacts with other patients outside hospital but was supported by meeting them at clinics.

I don't like the endless conversation about other peoples' diseases. I wasn't terribly lucky, put it that way. There wasn't anyone I madly wanted to keep up with. I've got a lot of support outside the hospital, so I don't really want any other kind of support. I see people at the tissue expander clinic each week. That's quite matey.

SS was in hospital at the same time as SM who was very anxious about having surgery. Also, another patient died when she was in hospital.

From Monday night S had us up to here (neck). I had to keep saying to myself 'Now just keep yourself calm. Don't let her get to you.' I got friendly with Sister J (nun). JB (nurse) came in and said she'd died. It felt quite flat that night. I haven't kept in touch with the others but I think you are better in a special unit. With it being all women it was good.

Two women felt that contact with other patients would prolong 'getting back to normal life'. MS had had a recurrence.

It's just something you want to put behind you and in a way if you are seeing people, you are reminded. There's another lady who had her operation the same

day and we are hoping to meet at radiotherapy. For me, it's important just to get back to normal.

Two women had close relatives and friends at home and for this reason did not see a need to maintain contacts with other patients.

8bii Peer group support for husbands

Northouse and Swain (1987) found that husbands of women with breast cancer experienced uncertainty and conflicting emotions equal to those of their wives. My data showed that peer groups occasionally offered support to respondents' partners. This created the opportunity for partners to become more aware of each other's feelings. SR's husband spoke to EM's husband on the phone.

D (husband) was sitting here and E phoned and said, 'D, I've got a new figure', because D has met E. T (E's husband) was saying, 'I wash it (prosthesis) in the washing machine.' We were having a laugh!

Husbands in MW's peer groups also supported each other.

We had a night out with our husbands a week ago. P (husband) and M's husband, D, have spoken a lot to each other which has been a help to them, particularly at the beginning because they had been so strong for us, and they kind of come down and you come back up. D and P felt they had nobody to talk to so we said, 'Let's give them your work phone number.' So we did and they met two or three times after that. They found M (counsellor) unapproachable. I don't know if it's the male-female thing, but they found they could talk to each other better.

8c Reactivated relationships

Some dormant relationships were reactivated following the diagnosis, especially when a relative or friend had had breast cancer. The secrecy and fear surrounding cancer was evident in the fact that respondents sometimes only learned about another's breast cancer after their own diagnosis. AH discovered a friend had had a mastectomy.

A friend who lives nearby who I'm going to pottery with this afternoon and who isn't someone I know terribly well, I hadn't realised she'd had a mastectomy. She came round and she was really helpful to talk with, just to talk through the whole thing.

DW felt reassured when she discovered that a friend had recovered from breast cancer. When women were willing to talk to others about their breast cancer, this often unlocked the door to receiving openness and support in return. JJ discovered that several of her acquaintances had had breast cancer.

It's funny working in the office of a garage. There are ladies that I never suspected but they've been through this. It's only because I mentioned it and they've said, 'I went through this five years ago.' It's helpful hearing about their experiences.

8d Permanent relationship changes

Although many changes in network members' attitudes and behaviour were temporary, some were more lasting. EM found her family more appreciative of her.

Before, I was here and that was it. Mother was here and you left a long list of 'I want. I need. Phone and make sure this is done.' I think me being ill has brought us a lot closer. It's made them more aware that they've got to do things. I think they have realised that they might not have had their mother and it's made them a lot more fussy about me doing things. If I cut my finger, they come rushing with elastoplast. They seem to think that the least wee nick and I'm going to have some raging infection.

Prior to her illness, SL's her family had been very dependent upon her.

I now feel I need to teach my son how to cook. I've done that and I'm making him work more. As for my daughter, she tries hard but she is a slow learner (mental handicap).

JJ's husband was a "workaholic", spending long hours in the family garage business. During JJ's illness he promised to change.

Sunday is family time. We've done lots of things that we should have done years ago, going for runs in the car, going out, taking the boys skiing and swimming and silly things like this. Life is too short. It's sad that it takes something like this to make you stop and take stock of things. It puts your priorities in place.

MW and her family appreciated each other more.

I think I value my family more, particularly my husband. You begin to take them for granted and they take you for granted. That's not there anymore. You plod along like every married couple do and when you face something like this, you realise how much you mean to each other again. P's said it, we all say it, 'What would we do if you weren't there? How would we cope with family? What would we do with the kids? How would we tell the children?'

MW had advanced cancer. Her husband, an anaesthetist, decided to spend more time with her.

He decided he would retire early. He decided last year when I was getting chemotherapy and he was getting home late. It meant I had to wait sometimes the whole day till he was finished. We thought, 'This is silly. we should be spending more time together, not muddling on trying to get this one to pick me up and he having the stress of not being able to do this.'

Sometimes illness caused respondents to review and change aspects of their lives. EC, a psychiatric nurse, found that her work attitudes had changed.

I went back to work but I had changed. I remember one of my old patients coming back to me and one of the staff said, 'It's J for you.' My heart sank. You can't do it that way. I thought, 'I really don't want to go any more. I don't want to sit and talk to this girl.' I'd never felt like that before. I'd always been keen to get involved. I've taken early retirement. It's the best decision I've made. I don't know whether F's (husband) retirement had anything to do with it.

IW found that cancer had made her more easy going.

I'm more tolerant. For instance when my grandchildren come in I couldn't care less what they did or if they broke things. My daughter in law says, 'Stop putting your feet on nanna's chair.' I say, 'Oh let them do it. They're not doing any harm.' It's definitely changed my attitude to life. I made up my mind I'm going to get on with life and I'm not going to dwell on it or think, 'Oh God I'm going to die next week.' I just feel that this episode in my life is over.

Summary

This chapter explored changes in respondents' relationships since their breast cancer diagnosis and their perceptions of support or strain resulting from these changes.

Support was defined as behaviour which gave attention to respondents to maintain/change identity. Respondents reported six main types of support. Most of each type, except experiential support, was provided by relatives. However, friends (companionship, confiding) and neighbours (practical support) supplemented network provisions. Most respondents with partners found these to be their main support.

Most stress resulted from network members being unable to cope with respondents' illness because of the perceived threat to their own identities and/or disruption in family routines and role expectations. There were 4 types of negative behaviour/attitude change; (i) network members seeking attention from respondents whose illness in some way threatened their own identity, (ii) network members not legitimating/recognising respondents' illness because of disruption of their own routines and expectations, (iii) network members were overprotective to respondents, affecting the latter's identity as capable and independent people, (iv) network members' behaviour undermined respondents' identities.

Thirteen respondents reported that one or more network members had shown no significant changes in behaviour since their breast cancer diagnosis. Eight were unable to be supportive because of illness, 4 had other problems.

Respondents wanted to reciprocate the support they received from others. Many expressed a desire to be less dependent on others and to get back to normal. However, they sought normality not equality in roles and relationships in which their identities were embedded and maintained. Whether they saw themselves as well supported depended on whether identities were maintained rather than whether they received as much support as they gave. Three ways of reciprocating support were; (i) early resumption of normal roles, (ii) protecting network members from stress, (iii) giving support to others.

Data indicated the balance of support and strain in respondents' networks. Seventy per cent of existing relationships offered respondents increased support after diagnosis, 20% showed negative changes and 10% were unchanged. In close, female-female relationships, support seemed more ambivalent than in close male-male relationships. More positive behavioural changes in male relationships may reflect the identity threat to females from breast cancer. Fourteen networks were predominantly supportive. Here relationships were good, network members had no serious illnesses to divert attention from respondents. They seemed able to cope with the patients' illness without seeing it as a threat to themselves or their position in the network. Eighteen networks offered mixed support and strain and one network was predominantly stressful.

Sometimes individual's and network members' perceptions that a crisis had passed did not coincide and problems occurred.

Respondents and network members' needs to maintain or make changes in their identities after diagnosis, resulted in changes to network membership, sometimes initiated by respondents, sometimes by network members. Some respondents lost relationships with people who felt threatened by their breast cancer. Respondents reported reactivating relationships which had been dormant and entering new relationships, especially with peers. Some also reported permanent, positive changes in their relationships with their network members since their breast cancer diagnosis.

Chapter Six

The Role of Formal Support in Identity Maintenance and Change

This chapter discusses respondents' perceptions of the roles of formal and informal support in maintaining and changing their identities during illness. While conceding that health care professionals were usually only temporary members of respondents' social networks, the data indicates that professional support played an important part in maintaining their identities during illness.

The support respondents received from health care professionals and especially from health visitors, was explored. Formal and informal support were compared and contrasted.

1 Appraisal support

People need to appraise the nature and seriousness of a crisis for their well-being, what support is available and the adequacy of their coping resources. Professional expertise played a vital role in this appraisal.

1a Informational support

Respondents indicated great needs for information about breast cancer and its treatment. Primary information sources were hospital medical and nursing staff. In the community, patients tended to refer to 'expert' hospital medical staff rather than their GPs. RW said;

If I'm really worried I know I can go to The Breast Unit. That's a big comfort I suppose because that is their speciality. They know what they are talking about. My own doctor didn't know what it was when I had pins and needles in my arms.

Health visitors recognised that patients looked to them for information and advice.

People are wanting to know. What's the radiotherapy going to be like? There's a bit of information giving and reassurance that it's not painful. The treatment

doesn't take long. I help them to feel, as the treatment progresses, that it's going okay. MW

A certain amount of medical knowledge is necessary. They are not coming to us with the more technical things, more the bits and pieces that happen day to day. RA

Seventeen respondents reported that health visitors helped them to cope better with medical problems. Lacking medical knowledge, informal sources could not usually provide such support. Health visitors prepared patients for treatments, advised them about treatment side-effects, assessing how they were coping and liaised with Breast Unit staff about problems. Patient, JL noted

I ask her things like, 'Will I take this or what?' I mean I can't keep running to the doctor because I'm sick all the time. I talk to her about my Diazepam, how I was frightened of getting addicted to them.

Health visitors also helped patients assess the significance of problems. JM worried about her wound condition.

I had her (HV) soon after the operation. I was having all this bother with fluid and the hardness. I thought she was very good.

EC was concerned about her breast lump's response to treatment.

She (HV) knew I was up to high doh, so she said, 'At least the lump is going down. You've got to work on that.'

SM wondered if she should report wound leakage.

She's (HV) put my mind at rest a couple of times when I thought this was leaking. She looked at it and said, 'It looks okay but if it gets any more, I'll see about it.' It saves me going to the doctor.

MW commented on the helpfulness of discussing her clinic consultations with the health visitor.

When you get home from clinic, two or three days later, you think, 'Oh they said' I can't retain all that much. I think it's because we're bombarded with so much at one time.

Knowing when to withhold unwanted information was also supportive. Having advanced cancer, AF was fearful about her future. Her health visitor was guided in giving information by what AF wanted to know.

I can tell her (HV) what I don't want to know. One of the doctors (GP) insisted on telling me, after me telling her I didn't want to know. That doctor didn't listen to me. J (HV) listens to me.

In contrast to health visitors' support which was tailored to individual needs, media articles/programmes about breast cancer were usually unhelpful to patients, increasing their fears as they applied the scenarios to their own situations.

Somebody gave me a book and I just opened it up and it said something like, 'Cancer spreads very quickly round the body.' I thought, 'That's the last thing. No I'm not going to read anything.' EC

2 Coping support

Professionals restored respondents' coping by helping them clarify problems, make decisions and deal with negative emotions. They also provided practical and material help.

2a Availability

Patients indicated that their coping ability increased with availability of professional support. Some respondents (13) said that health visitors' support was very important to their coping. This group included 3 women with advanced disease, 2 with inoperable tumours, 3 with large tumours and 2 with severe treatment side effects. Health visitors' support was intensive in terms of input, frequency and length of visits. For a further 17 respondents, health visitors' support was intensive but brief. Health visitors visited these patients less frequently than those in the first group but often supported them through a particular crisis.

Health visitors' availability reduced patients' uncertainty. Patients perceived them as accessible and approachable. Health visitors conveyed their accessibility by expressions of concern for patients' welfare.

I think it's helpful that someone (HV) is taking an interest in what's happening to you. DW

C (HV) has been very good throughout it all. She phoned me and said, 'How are you getting on? Do you want a chat?' MW

It just happened when she (HV) phoned, I was a bit worried about my other breast. I was waiting to go to the clinic about it. She was so concerned, she phoned back the next week. I was able to tell her it was alright. MS

My data agrees with previous research showing perceived rather than actual support to be important to coping. Health visitors' support was in the background, available if needed. In this respect health visitors were like professional attachment figures. Bowlby (1975) noted;

Presence of an attachment figure is to be understood as implying ready accessibility rather than actual and immediate presence, and absence implies inaccessibility. Not only must an attachment figure be accessible but he/she must be willing to respond in an appropriate way in regard to someone who is afraid.
p. 234

Knowledge that they could contact the health visitor, increased patients' security.

It's nice just having someone who's in the background and you can call on them whenever you need them which is the important thing. CB

I feel I could phone her if I was worried about anything. I do see her at the surgery. She said she'd pop round. I find her a great help. EC

She (HV) left me her number to ring, if I wanted a chat or anything. You feel with the whole team you can just ring them and say, 'Look I'm feeling like this.'
EM

Sometimes their availability was determined by health visitors who decided upon visiting frequency, the patient being invited to contact them if necessary before the next appointment.

She's very nice. She'll call again in a month's time.

She visited twice. She said she'd give me a ring quite soon.

Sometimes health visitors' availability was ambivalent.

She's been twice She doesn't feel she needs to come back, but I've got her number to ring if I need her.

Availability of support from health visitors was patient directed in 54% of cases, women perceiving it as available whenever they wanted it.

She's my lifeline. I know she's there. I suppose it's a bit like a kid with a night light. You know it's there if you want it. She really has made a tremendous difference. AF

If I hadn't had people to talk to I don't know where I'd have been. It's back up you can't get just phoning Cancer Link. She's been my crutch for the past few weeks. JL

AB and SR valued continuity of care from the same person.

If there had been no health visitor and I wanted to ask a question, I'd have rung the ward. On the other hand it would quite likely have been a nurse I had never

come across. So it would be nicer to contact someone whose face I knew and who knows me also. AB

The very idea that she had left her number meant I could phone her and you know that it's somebody that knows you. SR

2b Psychological support

Most patients reported that health visitors enabled them to cope better with psychological problems. Health visitors provided psychotherapeutic support, encouraging patients to explore and express their feelings. Brown and Pedder (1979) listed the attributes of psychotherapy;

A relationship of trust, allowing communication in words, promotes the understanding and integration of previously unacknowledged aspects of the self and relationships.

They maintained that much informal psychotherapy could take place between friends and in informal groups. Was there any difference then in the type of psychotherapy practised by health visitors compared with that given by patients' kin and friends? Health visitors' support appeared to follow a more formal 'counselling' model, often incorporated the three aspects of Egan's (1990) helping model.

- 1 Identifying and clarifying problem situations
- 2 Developing a preferred scenario-helping people make decisions and choices
- 3 Making plans/developing coping

Health visitor, CR, felt that encouraging patients to talk through problems was important.

I think it's being a sounding board, letting them talk. Things tend to pop out when they are doing that. You can pick bits up that you can maybe do something about. You can sometimes talk them through things, even family upsets because they see things differently when they are unhappy.

JP (HV) told her nurse manager that she was 'interested in counselling based work' and saw support of patients with breast cancer as being 'mainly psychological.' DL (HV) thought it was therapeutic to encourage patients to talk to her, an 'outsider', about their feelings and problems, recognising that some felt unable to do so with families.

I think it's best therapy just to talk. I think it depends on the type of person you are and the type of family or friends you have, how supportive they are and how much you feel you can talk to them.

MM (HV) felt some patients protected their doctors, not expressing their anxieties.

Just listening was my main support for JL. A lot of patients feel they can't tell the doctor how bad they feel because they feel they are letting them down in a way.

RA (HV) found that three of her six patients needed her psychological support and availability.

AH, SM, and EC needed support, sometimes information, sometimes just that I'm there. They are much more themselves in their own homes.

Patients said that health visitors helped them explore their psychological problems and coping. Eve C, a psychiatric nurse, initially felt she did not need a health visitor's support but later revised her opinion.

My initial reaction was 'I'll not be needing it', but she was excellent. I think as nurses we tend to think we don't need any of that but it was very useful. I think she felt I was doing alright and had made a reasonable adjustment to what was going to happen (mastectomy).

Eve C's health visitor RA commented;

We looked at all the different aspects, her relationships and the support, what she was doing, how she was feeling about it all, how she was coping.

Health visitors assessed whether patients were anxious or depressed, using the Domiciliary Assessment Form (Appendix 6).

We discuss how I'm doing on the chemotherapy and how I feel about it. She (HV) asks how I'm managing in the house. I told her I'm managing quite well. We talked about what my good days were and what my bad days were. JC

MM (HV) noted that JC was having severe chemotherapy side effects but had developed a positive approach to her treatment.

She stays in hospital overnight, having chemotherapy and comes home by taxi. She is tired for a few days and then feels better over the weekend. Her hair has started to fall out but she has chosen a wig and is coping well. Her tumour has started to shrink so she's feeling very positive about her treatment.

2c Practical support

Health visitors assessed patients' need for practical help and eligibility for material resources. Financial problems arose in 10 cases because of respondents' or their partners' low income or unemployment. Health visitor, JP, had not previously considered that as part of her role.

In the past, I felt financial help was a social work role.

Health visitors assisted several patients in applying for benefits and grants.

She (HV) discusses with me about putting in for allowances. She brought the forms for mobility for me. She's helped me moneywise. She got the phone put in. She's got my taxi card. JL

Having advanced cancer, AF suffered from backache from bone metastases. Her health visitor tactfully offered help.

I really do feel this chair is making me worse. She's (HV) going to find out if she can get me an orthopaedic chair. She doesn't make me feel like a charity case.

AF's health visitor also contacted various agencies about financing a holiday. CB's health visitor applied on her behalf to charities to clear her debts before she became too ill to work. MB, with inoperable cancer, lived on a low income, in a cramped hotel room. Her health visitor's application to the Housing Department resulted in her moving into a comfortable flat. She also obtained for her £80 for clothing, a furniture grant, Attendance and Mobility Allowances. Voluntary transport to hospital clinics was arranged by health visitors for some patients.

3 The role of professional support in maintaining patients' identities

Respondents reported receiving professional and informal support for their vulnerable identities. To cope with their illness, women needed both to maintain and make changes to aspects of their identities. The threat from breast cancer was a long term issue and after the initial crisis had passed, support needed to deal with it came mainly from their informal networks. However, some types of identity support came mainly from professional sources and was particularly important at certain stages of the illness.

3a Permanence

Most patients' main anxiety was fear of recurrence and uncertainty about the future.. Doctors could not honestly reassure them that cancer would not recur. EA talked to her GP.

I did say that I had been focusing my attentions a wee bit on the negative side and were there any micrometastases. He said, 'Well nobody really knows with cancer.' I said to the doctor, 'You go and get your gall bladder removed and you know that that's it. With cancer, people always have this question mark hanging over it. Is it going to come back and how long are you going to live?'

Health visitors helped patients cope with these anxieties, not with false reassurance but encouraging them to talk about fears and by providing appropriate medical information. CR (HV) noted that AB was particularly anxious at clinic appointments and timed visits to coincide with these.

She says from time to time it comes back to her that the cancer could come back. She appreciates that and she thinks she's coming to terms with it. I tend to see her just after her clinic appointments because I feel that if there are any pieces to be picked up, she's got an ear to bend.

JM felt depressed at seeing other patients ill with cancer when she was still feeling vulnerable. Additionally, she was concerned about the significance of cellulitis in her breast following radiotherapy.

I got a bit depressed about the third or fourth week of radiotherapy. It was getting to me, going there every day and seeing other patients. You were sympathetic but you didn't want to see that. I've been left with this solid breast. Dr R (radiotherapy consultant) keeps saying it's cellulitis and it's going to take a long time to go away. I worried about it.

JM's health visitor, CR, noted her continuing anxiety about possible recurrence.

She then told me she was extremely worried about the hard red swelling in the right breast which she had mentioned the last time she was in the clinic but felt that Dr R had rather fobbed her off. As she was going to clinic the next day, it was decided that she should mention it more forcefully. I would ring her after her appointment to see if she had had a satisfactory explanation for her problems.

Patient, SL, felt that she was in a dark tunnel and without a future.

I thought I would never see the end of the tunnel. It was all so dark. I knew nothing about what was going to happen. I knew nothing about the treatment. I was so depressed. I kept thinking about the future. I kept thinking about my children.

Her health visitor encouraged a more positive outlook by discussing her fears and providing information about treatment. Sometimes fear about the future expressed itself in anger especially when patients felt there had been avoidable delays in diagnosis which could affect their prognoses. Having reported a breast lump to her GP several months previously, MW's patient, JJ, had been angry at the delay in diagnosing her breast cancer. MW allowed her to express these feelings.

At my first contact with J, she was very angry and talked about suing. I saw her again some weeks later and she didn't express much anger then.

Health visitor, RA, detected 'a lot of bitterness and anger' in her patient, SM, over a delayed diagnosis. Sometimes health visitors assisted patients to assess their progress by talking about other patients' similar experiences. JL was comforted by knowing that other patients had survived.

She (HV) told me that there's some other patient who has had a (radiotherapy) reaction like that and I don't feel so bad about it. I ask about different people and how they are coping.

Patients receiving treatments for inoperable breast cancer felt particularly fearful of the future. AC, receiving radiotherapy, felt depressed and anxious.

By the Friday afternoon I was in tears and I continued through Saturday and Sunday. Then on Monday morning I went into the office and floods of tears as soon as I went in. I thought, 'This is no good. I need help.' So I phoned M (health visitor). It could be the menopause. It could be stopping smoking. It could be the fact that I know I've got breast cancer and I know it's not life threatening but it's not nice knowing I've got it. It's probably a combination of all three. She (HV) has experience of other patients going through the same treatment.

Her health visitor MW, responded to AC's distress by meeting her for lunch and encouraging her to talk about her feelings. MW noted that her role as an 'outsider' was helpful to AC.

She does talk to her husband but I think it's helpful that I'm someone outside the family.

Recurrence was a particularly difficult time to feel hopeful about the future. MS had been shocked at recurrence of her breast cancer from five years previously. Between check ups, she had been able to forget her disease. Her health visitor helped her during a period of depression.

One day last week I got quite depressed, quite gloomy about things and I just had to snap myself out of it. It was very difficult. I really did start to think all sorts of things. She (HV) was concerned about me. I'm feeling more positive now. I

didn't even tell my husband until it was about two days after I'd been to the doctor with the lump.

Helping patients with advanced cancer to retain hope was difficult. AF coped by putting her illness to the back of her mind, sometimes more successfully than others. She was not helped by her GP.

How long can you go on with not knowing - mind you part of me doesn't want to know - what's happening? It's like being in limbo. It's been like that for two years. When you think you've got over one bit, something else crops up. (crying). For a long time I worried, then it sort of dawned on me that I was still here. It wasn't so serious. You could put it in the background. Then that stupid doctor (GP) made me think it was going to be my last Christmas. I wouldn't even see January. From then on it was difficult.

AF's health visitor JP commented;

A, with having advanced disease, admits to being terrified. There have been all sorts of social, financial and practical type things which have been necessary, but she's not always willing to accept, being so independent. I've noticed if I've left it for a while she'll come back and ask.

JB had also been frightened by her GP's apparently pessimistic view of her future and his inability to see that denial was helping her to cope.

I feel that he (GP) takes a more pessimistic view of my illness. I always get the impression when he speaks to me that he is surprised that I'm as well as I am. He seems to think it was much worse than I thought.

3b Health

Respondents' self concepts as 'well women' were threatened, since they faced future uncertainty about their health. It was important that they were able to put their breast cancer experience into perspective. First, they needed to explore their feelings openly. AH's family did not encourage her to discuss her feelings.

When Christmas was over and I was going for the tissue expander, it sort of brought it all back and it was sorer than I expected it to be. I'd got back into my old pattern of, 'I'll deal with that later.' Talking to people helped.

AH's health visitor, RA, encouraged her to think positively about her medical progress and to have the things which worried her investigated.

She was worrying about the future because cancer is a systemic condition and it was already in one gland. She had herself dead and buried. She wanted to have a liver scan. I discussed that with her GP and Sister T. She was having a new pain and hadn't told anyone. I shared it with Dr T (GP) confidentially and she examined her. I'm trying to arrange visualisation therapy with Dr K

(psychologist). She asked me about it. She'd had three friends who all died of breast cancer. Her father died of cancer. The maternal grandmother died of cancer, and there were people in the street with breast cancer. So she'd had enough to make her frightened.

EC worried about her progress and talked to her health visitor, JP.

She's helped me with this. I like to know when she's coming, then I can store up these fears that I have.

JP, recognised EC's need to talk both about her medical and family problems.

E is unable to concentrate. She was very talkative and stressed initially but relaxed a little during my visit. She is worried about her husband and confided that he has an alcohol problem. She's worried about her future.

3c Independence and autonomy

The illness and treatment undermined respondents' perceptions of their independence and autonomy. Almost a third of them had periods of depression arising from feelings of lack of control over their illness. Maier and Seligman (1976) proposed a 'learned helplessness' theory of depression, suggesting that an anxious response to a stressful situation could lead to depression if the individual believed it was impossible to control the situation. Being in control was fundamentally important in humans. MW sometimes felt depressed.

I've been very positive from the Monday evening when it all flooded out. We were saying this on Monday the four of us (patients) that were together. It's something you've got to try and go through with a positive attitude because if not, you are just going to look for all the down side all the time. Your own self esteem goes.

EM had suppressed her feelings of depression which emerged unexpectedly after her discharge home.

I said to my husband, 'Oh it's nice to be home in bed with the lights out.' Two minutes later the tears were tripping me. I don't know why. It was the one thing everyone looks forward to, coming out of hospital. You keep it hoarded up all day and it's a relief letting it out. There have been one or two times when I've felt low enough that I wished they hadn't done the operation.

Health visitors were usually aware of patients' depression. PY was anxious about the future and whether her skin would heal after radiotherapy. She developed a fear of leaving the house.

I thought I wouldn't have to go through this again. Doctor had said it wouldn't happen again. It makes me feel so miserable and depressed. What will they do if I don't respond to the radium?

NB (health visitor), tried to help PY to think more positively.

P is her own worst enemy because her daughter offered to come and take her through to Gourrock for a week but she won't go. I have been trying to say to her, 'This would do you the world of good even if it's just for three days.' I can appreciate how difficult it is for her to go anywhere.

Another patient, JL, also had problems with her treatment and became reluctant to leave her house. MM, the health visitor, encouraged her to be more independent.

She's latched on to me a bit. She says, 'Now you're not going to leave me. You'll be back next Wednesday. Have you written it in your diary?' So we just laugh about it now. I've seen her every week really. I think this is a temporary thing and it's all part of her anxiety. I think if we can get her out into some of these other groups, she'll not be needing me so much.

MM encouraged JL to join a local support group for her own and her husband's benefit. JL and her husband both commented on this;

JL M's (HV) forever at me to walk to the end of the street. I got agoraphobic after my operation but that was because I was sick.

Husband

It helped me quite a lot. She's a prisoner in the house and she's made me one as well, apart from walking the dog. She (HV) reckons a part time job would be good for both of us. She said J would be doing her own housework and standing on her own feet that way.

Decision making is an important aspect of autonomy. Medical staff encouraged patients' involvement in treatment decisions and treatment trials. However, many patients were reluctant to take responsibility for decisions that might, they felt, influence prognosis, preferring to defer to medical opinion or make joint decisions with the doctors. There were exceptions. ES felt that the decision to have a lumpectomy was hers.

I asked the doctor what was the actual rate of survival if I had a lumpectomy. You had just the same chance of surviving having a lumpectomy as having a mastectomy. He said it was entirely up to myself. He said that sometimes women can't come to terms with losing a breast. Well I didn't feel that. If it was a case of it's going to be 100% safe I'd have said, 'Take it off.' If it wasn't going to be any safer I said, 'I'll have the lumpectomy.' It was totally my decision.

RW who had had a previous mastectomy, also had definite ideas about her treatment.

I know there are some people who won't put up with their breast being taken off. They'd rather just have a lumpectomy. I wanted it all away. In fact this time I think I could probably have got away with a lumpectomy. I think it made it easier for him (doctor) because I said, 'If there's disease there, take it all away.'

EA expressed a preference for chemotherapy over radiotherapy. However, she agreed to enter the treatment trials, knowing that she might 'draw' radiotherapy as her treatment. She asked the consultant to put aside his professional status and advise her informally about her treatment.

I thought I'd rather have intravenous fluids (chemotherapy) than the radiotherapy. I asked the consultant what would he choose if it were someone related to him. He said the same as what I was thinking, so I thought, 'I'll go for that.' I put myself into the trials and it came back that I wouldn't be getting radiotherapy. He said, 'That's what you wanted anyway isn't it.' I said, 'That's right.'

AD, a finance consultant, wanted as much information about her treatment as possible.

Dr A was always condemning me because I was asking her for the statistics. She says it's not something they volunteer because most people can't cope with that. I said, 'I would rather know.' There's no point in kidding yourself. Dr A gave me some of the papers she'd written to read. The tumour was oestrogen receptor positive. With one as high as mine, the chances of hormones working were very high. But then of course it failed. Looking up the statistics again, if you've got a high oestrogen receptor and it fails to respond to hormone treatment, then you've got next to no chance of the chemotherapy working. Of course, that's what happened. Then, in a way, I was well prepared for the chemotherapy not to work. Twelve weeks chemotherapy and it (tumour) went straight back to its original size. I didn't want to go through any more chemotherapy. Mr C talked to me for a quarter of an hour and convinced me that I should go through with it.

Some patients with large tumours, were not asked to make treatment decisions but were recommended certain treatments. MH and her husband were content to leave the treatment decisions to the doctors. Mr H commented;

We had a slight problem with the thought of the chemotherapy which was going to reduce the size of the lump to virtually nothing. I said, 'Why do we need surgery if it's going to go away?' They explained that with a lump over a certain size, the breast had to come off. They are the guys that have all the experience. I think they had agreed on what was the right thing to do but they did involve us and explain it to us.

BI's story illustrates the difficulties confronting professionals when trying to involve patients in treatment decisions. Initially, BI had expressed to the nurse counsellor, a dislike of having mastectomy. She also found it difficult to visualise what was

involved in a 'flap' breast reconstruction. The nurse counsellor introduced BI to another patient who had had a nipple reconstruction.

The pictures in the book looked all crinkly and very unpleasant. I thought, 'I don't think I would like to look like that. That (reconstruction) would be horrible.' M (counsellor) had said, 'How would you feel about a mastectomy?' The thought had never entered my head for a single minute because the lump was very small. I could see no reason why they would need to do a mastectomy, so she noted that down.

The surgeon noted her opposition to mastectomy.

Mr C told me that possibly they would just be able to remove the lump and a sample of the glands, but on the other hand, because of my size, it would probably be more appropriate for wearing a prosthesis afterwards, if they were to do a mastectomy. He asked me, 'How do you feel about that?'

At this point, BI wanted to leave the decision to the doctor. Because of her initial wish not to have a mastectomy, the surgeon felt that she should make the decision. BI found coping with this difficult.

I tried to say, 'If you, as the specialist, feel that mastectomy is what is best, then I'll take your word for it.' He wouldn't listen to that. He said, 'I must send you to see the radiologist.' The radiologist said, 'I think we can do a nice job here and just do a lumpectomy.' In the meantime, my husband had been trying to persuade me that if they felt they could do a satisfactory job with a lumpectomy, then they should do that. If they felt, in the long term, that it was going to be better to do the mastectomy, that would be the thing to do. That would leave the decision to them. They wouldn't accept that. I went in and saw MD (surgeon). He said, 'I promise you faithfully we won't do a mastectomy and that you won't wake up and find that you have had a mastectomy.' I couldn't believe my ears. It didn't seem real that a surgeon could be speaking like this to me. Neil (husband) said, 'If she decides she wants a mastectomy, is that going to cause any problems?' 'Oh, no problems at all,' he said.

Even after her hospital admission, BI felt unable to decide about her surgery. She repeated that she wanted the doctors to decide for her.

The next Monday when I went in, I couldn't come to any decision. I really wanted to leave the decision to them. That particular day was the worst of all because they started on me from the minute I went into the place. It was like a brain washing process. I was wanting them to decide what to do with me. They wouldn't do that. They kept throwing it back and it went on all day long.

Finally, BI was helped by a house doctor speaking to her personally rather than professionally.

The house doctor came to me again. He was saying, 'If you were my mother, I'd advise you to have a mastectomy.' I said, 'All right son. I'm not arguing. I'm just making the point that I'm not qualified to make this decision. I'm not medically

qualified and you are. You are the people who must tell me what's the right thing to do.' Irrespective of how you feel about it psychologically, you want the right decision to be made.

HM also felt that doctors should make medical treatment decisions.

The doctor said, 'How do you feel about it all?' Well I was practically speechless. I'd rather the doctor had said, 'Look, it needs to be taken away' instead of going a roundabout way of asking you. You could make the wrong choice. The doctors should advise you more, not say, 'What do you think?'

JM and her family felt that it was unfair to ask patients to make decisions about medical treatment.

He (husband) didn't think it was very fair putting that onus on anyone. He didn't think it was fair to expect a patient to make a decision like that. I said to Dr D, 'What do I know about radium?' I said, 'Nothing.' I know nothing about cancer. I said, 'I'm believing every word you're telling me about what you've done for me, but I don't know anything about cancer or radium.'

'Preference' decisions about cosmetic surgery were usually much more influenced by patients' own attitudes. While health visitors did not help patients to make medical treatment decisions, they sometimes helped them to make 'preference decisions' about cosmetic matters such as breast reconstruction or to evaluate a choice already made. SS had a infected breast implant removed and discussed possible reinsertion with CR, her health visitor who commented;

At the moment she's saying, 'No way' is she having any more done. She said, 'It's as though it wasn't meant.' I wonder if she really wanted it in the first place. Her mum had expressed concern about it but she'd listened to all the arguments. Then she went along with it. She said, 'Really at my age and having been married for 25 years and my husband's not complaining.' So at the moment she's saying, 'Definitely not.' I've been saying, 'Well nobody is going to put pressure on you.' I think she feels more in control this time round.

Cotton *et al.* (1991) interviewed 20 women with breast cancer who had made a choice of treatment one year earlier, on whether they were content with their decisions. All had been seen by nurse counsellors. Results supported other studies showing that giving choice is feasible and probably beneficial when information and counselling needs are met. However, it indicated a need for more research, since three women wished they had conserved their breasts rather than had mastectomy.

3d Body image and sexuality

Health visitors recognised that coming to terms with feelings about body image and sexuality was an important part of patients' recovery from breast cancer and discussed these topics with them. However, exploring effects of the disease and treatment on sexual relationships was more difficult. JJ was having problems with her appearance after breast reconstruction and discussed it with her health visitor.

I had problems with my overall look. At the second visit it was really bothering me. She (HV) was saying she thought it (breast reconstruction) would drop, not to worry about it. That helped. As far as she was concerned it was early days yet.

JJ's health visitor, MW, discussed possible effects of her illness and surgery on her marital relationship.

The second time I saw her, the implant was a bit high but sometimes they do drop a bit. This didn't. I spoke to her last week and she said that the surgeon had agreed that it was a bit high and they were going to do something about it. It was the only thing really that was upsetting her. She has quite a good, close relationship with her husband. He's seen the extent of the surgery and it hasn't upset him.

Eve C was depressed at having to have a mastectomy after an initial local excision of her breast lump. Her health visitor, RA, called to encourage her.

It was nice seeing her because I certainly was upset about going back again. I think that's why she came when she did, to see what frame of mind I was in about going back and to give me a wee bit of encouragement.

RA assessed how Eve C was coping and how her breast cancer might have affected her relationship with her husband.

She's feeling much better about her appearance now that she's got some cleavage and there is a shape. She describes it as, 'not really bad at all.' She said her husband was relieved when he woke up and found her breaking her heart. He wondered when it was going to come. The first time I didn't feel easy talking about the sexual aspects. Last time when I was there I asked and she said, 'Yes it had made some difference.' She hadn't felt like it at all. He was very understanding but it made some difference.'

Several months after her mastectomy, SM was thinking about her cancer less, mainly at night because she disliked taking off her prosthesis.

I'm not thinking so much about the operation, definitely no. The only time I think about it is with me and my husband.

Her health visitor who commented;

S is having some problems putting her prosthesis 'in its box' at night. I suggested wearing a maternity bra at night (with a softie or prosthesis) and keeping her day bra intact.

LB, a young patient of 28, worried about how her breast cancer might affect her future prospects for parenthood.

They (doctors) say that you shouldn't have a family for a couple of years. They said it would be better not to become pregnant, especially not when I'm having chemotherapy. I suppose if you became pregnant there would be a change in your hormones?

LB discussed these anxieties with her health visitor, JP who commented;

She seemed to be quite worried about her future prospects of having a baby. She's a young woman and they've only been married two years and within the next two years they had been thinking they would have a baby. She's wondering, 'Why? Why?' Her husband seems very supportive and they can talk together about things. I don't think she has really discussed her feelings about having a baby with the doctors. I think she's assuming someone is going to advise her. I'll discuss it with her again next time I see her.

MW had to have her breast implant removed. Her health visitor, CR, commented on her reactions,

M is looking much better. She was very disappointed that she had lost the prosthesis but relieved that the infection was under control at last.

Two women found it easier to discuss their feelings about breast surgery with a health visitor than with male family members.

It's helpful to talk to a woman. I've got a house full of men. There's only certain things you can say. I felt through it all, 'If I'd had a girl in the house.' MM

She seemed to hit it just at the right time, when I needed someone to talk to. I feel it's possibly that I don't have an awful lot of female people coming in. I mean there's lots of my friends but most of the day is spent with men or on my own. EM

3e Relationships

Relationships are important in maintaining individuals' identities, self esteem and security. Family therapists have stressed clients' needs cannot be viewed in isolation from those of their families who also need support. Studying families of children with cystic fibrosis, Whyte (1989) emphasised the importance of nurses assessing families' support needs.

Initially the focus will properly be on the child who has the health problem. It is worthwhile however, to make it clear at the first visit, that the nurse is aware of the potential stresses on the family, and is interested in the health and welfare of each family member. p. 325

Luker and Orr (1985) argued that health visiting was about working with families but noted difficulties with this definition;

There is difficulty in ascertaining whose needs are paramount within a family and to what extent family conflict is functional to survival of the unit, and to what extent health visiting intervention will be welcomed and utilised. p. 85

In Chapter 6, it was shown that respondents' relationships were impaired if their network members felt threatened by the illness or effects of the illness on their lives. Many women perceived health visitors to be supportive of these relationships and thus indirectly, of their own identities. In 14 instances, health visitors contacted patients' network members. They spoke to children, finding out how they were coping. Sometimes husbands wanted support. Visiting AC, the health visitor noted that;

Her husband was present and asked lots of questions.

Although working, EM's husband was always home when MW, health visitor, visited. SM's health visitor, RA, noticed that S's husband was usually present when she visited.

The first couple of times I was there, he cleared off out. The time before last he stayed over by the window and every so often participated. This last time he sat down with us. I thought it was good. He was as upset as she was (over bereavements).

Several women were anxious about children's negative reactions to their illness. MW's health visitor, CR, made a point of meeting her children to assess their coping. CR noted that MW's son was 'clingy', her daughter 'withdrawn' and her husband over-protective.

P, the fifteen year old girl, seemed rather embarrassed and shy. I suspect it has been difficult for her coping with her mum's illness and its implications, especially in a year when she has important examinations. The ten year old son, by contrast, was full of beans and desperate to tell mum what he had been up to at school and where was lunch!

SM's daughter was causing problems at school.

I was telling her I had a bit of bother with A (daughter). She was upset. She was truanting and then fainting at school. She (health visitor) knows about the family.

Patients could sometimes confide in their health visitors what they felt unable to share with their network members. The health visitor's professional relationship was supportive because it was not embedded in any past or future roles nor carried any expectations of reciprocity as did relationships with kin and friends. During illness, some respondents felt obliged to protect network members by hiding their true feelings. Eleven patients commented on the supportiveness of confiding in someone 'outside' their networks.

You can talk to her (HV) and you can explain how you are feeling and you can't always do that with your family. I'm not wanting to put any more pressure on them.

I didn't want to talk to my mum about it as she's older. My mum is 73 and she's got enough on her plate.

Health visitors encouraged patients to discuss how their relationships were affected by illness. Patients perceived health visitors to be detached, not overinvolved. HM talked to her health visitor, DL.

It's good to have somebody to talk to who is outside the situation, who is not emotionally involved in any way because all your people have this great hang up about cancer. Everybody you talk to is emotionally involved, so it's quite good to have somebody you can talk to who you don't have to think what to say to. With most other people you are thinking of the effect of what you say on them and how far you can push your friendship without asking too much of it, well especially women of my sort of age. They can always see it happening to them.

DL was aware of HM's need to discuss her worries with someone outside the family.

I don't know how much she feels able to talk to him (husband) because he's obviously still recovering. He had a subarachnoid haemorrhage. Once she started talking, she talked and talked and covered a whole range of topics. I think she surprised herself. I was there as somebody for her to talk to because I didn't even get my opening gambit in. At the end of the interview she said something like she was amazed how much better she felt, or something that made me feel I had done something for her.

Eve C felt the need to protect her husband and son from bad news. Initially, she did not tell her son, living away from home, about her illness, finding it easier to discuss her feelings with health visitor, RA.

Oh it was definitely very beneficial. You can't talk to the family the same way. If you have been troubled or very distressed you can't put that onto your family. You've got to put a face on it in a way, well not all the time. If I wanted a good cry F (husband) would be the first to be comforting.

RA, the health visitor, was aware of Eve C's unwillingness to discuss her real feelings with her family.

She didn't tell her son. He's coming up this weekend to see whether she's told him the whole truth. He lives in Keswick and she didn't tell him till it was all over. When I asked her who she had shared her real feelings with, it was her friend. She talks about her husband a bit but not a lot.

After discharge home, SL was in tears most of the time and support from a 'neutral' health visitor was important.

Nobody would come at that time because I was feeling sorry for myself. Naturally you feel that with somebody neutral, somebody completely a professional person, you could cry on that person's shoulder better than with your friend or relative. You feel you don't want to trouble them.

SL's health visitor, DL, recognised her need to protect her family from stress.

She's anxious about her daughter (handicapped) and her future. She was still a bit weepy while she was talking to me but she said she'd really got over the weepy stage. She was certainly a different person the second time I went. She was behaving like an invalid the first time but the second time she seemed to have regained her confidence.

Glaser and Strauss' (1965) research showed that communication within families could become closed when one member was seriously ill and others became anxious. There was a state of 'closed awareness' in which family members were aware of the situation but were unable to discuss their concerns. This inhibited communication existed in some of my respondents' families and they felt able to discuss with health visitors concerns they felt unable to mention to families or friends.

That's what you need sometimes, someone to be an outsider coming in that you can bounce things off. I said to her (HV), 'I think it's quite normal when you've got a family. You've got to put this facade on. You've got to get up and do things because the family is around. You don't want to upset them.' You also put up this front to everyone else. When my mother phones, I say, 'I'm fine mum.' I'm sitting thinking, 'Oh no I'm not.' She (HV) is someone outside the immediate family that I can discuss some things with. I can talk about how my husband feels. It's safe to talk to her about private things confidentially. She wouldn't be shocked.
MW

MW's health visitor, CR, was aware of M's need for a confidant.

Family relationships have been difficult. Her husband is so worried he is fussing over her and she finds this difficult as he is not normally a demonstrative man. I think she feels she can talk to me about things medical which she perhaps would feel she couldn't with others. I discussed the children's reactions to their mother's illness.

SM could express her feelings to the health visitor.

You can talk to her and you can explain how you are feeling and you can't always do this with your family because you don't want to worry them.

CB had difficult relationships with her family.

It's nice to have someone who knows what I'm talking about, but is sort of an outsider. It helps because I'm beginning to see it from her point of view as well as my own. The family is hopeless at this.

Her health visitor commented;

The family won't discuss her prognosis. I will make myself available for this. C likes to have contact with someone outside the family.

Health visitors' detached approach was felt by some patients to be more supportive than an emotional response when they were very anxious. AF was unwilling to confide in her family but appreciated her health visitor's approach.

She's very important. She's at the hub (of contacts). She's easy to talk to. She doesn't feel like a health visitor. She's the person I talk to most. She's sympathetic but not too sympathetic because I can't take that.

LB felt that some of her network members were afraid of saying the wrong things.

It's nice just to speak to someone totally outside whatever, outside the family, outside the hospital, I suppose people you know quite well can be frightened to say the wrong thing or know how to react. Even going back to work, obviously everyone is quite concerned. I think some are a bit wary about what to say and what not to say. I think it's easier to be open about things and not try to cover up.

EM valued the health visitor's more detached support. There was less need to conceal her negative feelings.

She (HV) has a more detached view than the immediate family or the hospital doctors. That's helpful.

Even supportive families were sometimes overprotective.

It was all right the family all backing me up but because I was so depressed, they were all sympathising. She (HV) was very good. JM

Some respondents also protected their doctors from their anxieties, putting up with discomforts without complaint, presenting a bright face. One health visitor attending the Breast Unit outpatient clinics noted;

The thing that struck me about those clinic sessions was what a false impression the doctors might get of the patients. The patients, on the whole were quite bright and positive with the doctors and joked with them. You know how at some of the clinics, the patients would stay in the rooms and get undressed. I would stay with the patients and they would say, 'This is a nightmare' or something totally opposite to how it sounded with the doctor.

4 Maintaining health visitors' professional identities

Peoples' identities are maintained or rejected in their social interactions. Professionals are not immune from this process in their interactions with clients. Health visitors reported how aspects of their professional identities were threatened or supported in interactions with patients. The following factors were important to health visitors' professional self images.

Competence

Achievement

Doing a worthwhile job

Being valued by clients (recognition)

Researchers have shown these factors to be important in job satisfaction. For example, in a study of accountants and engineers, Herzberg *et al.* (1967), found that recognition, sense of achievement, intrinsic satisfaction in the work, responsibility and opportunity for advancement increased respondents' job satisfaction.

4a Competence

Professional people progress from noviceship to expertise. Health visitors perceived themselves as experts in child development but relatively ignorant of breast cancer care. At the outset of the research, they completed a questionnaire assessing their perceptions of their existing knowledge, skills and confidence in breast cancer care. All except one with previous experience, perceived their knowledge, skills and confidence in medical aspects of breast cancer care to be deficient. They felt more knowledgeable, skilled and confident about giving psychological support. Nine months later, the health visitors completed the same questionnaire. After education and some experience, they perceived their knowledge, skills and confidence to have

increased in all aspects of breast cancer care (Appendices 3 and 8). Initially, their identities as competent professionals were threatened because they felt they had insufficient knowledge to provide the patients with the support they required. One health visitor, CR, reported;

AB (patient) wants to know more about the trials. She asked me things I really feel I couldn't give the answers to. I got tied in knots because I'd nothing written down with me. I said, 'I'll tell you the next time I come.'

Health visitors were sometimes unable to answer patients' questions. RA reported;

They ask things like, 'How long do people stay off work after a mastectomy?' I can't answer with real confidence. I've got very little experience to base it on. With babies' feeding problems you are doing it day in and day out.

Health visitors felt that patients regarded them as experts whereas they still had much to learn. CR commented;

JM was extremely worried about a hard, hot red swelling in the lower aspect of her right breast. On examination, it looked like cellulitis but I explained that I was not an expert but would find out about it for her.

DL had no confidence in her ability to support patients with breast cancer prior to becoming involved in the research.

I still don't feel anything like an expert and they still ask things which I can't answer. I can see they look on me as an expert. That's going to come with practice. I couldn't remember all the things I was supposed to ask and with HM, (patient) of all the things we didn't cover, I realise it was the psychological adjustment. So for my own purposes I want to cover that at the next interview. The more patients I have, the more I retain. I certainly feel better informed than I was.

DL went on to note the consequences of her previous lack of confidence.

The lack of preparation was the main thing. I used to think, 'Oh my God, I'm not going to go there. What do I know about mastectomies?' I would put it off and make it my lowest priority which was a great excuse for not doing it. Then I'd decide it was too late. It was all really down to having no confidence in what I was doing. Then H (liaison HV) and M (counsellor) produced this pack which was a help but at the same time it was all written and you need to have actual experience of the clinics rather than just reading it all.

Health visitors worried about giving patients wrong information or making an incomplete assessment of problems. CR reported;

With JM I really felt I hadn't done it right. On reflection, her anxiety level was greater than I'd anticipated, even though she had her family round her. I should have been there more often.

RW felt particularly unsure of her self with patient, EC, a psychiatric nurse.

E is actually a very capable lady. I can't say I felt it has been really good for her to have had me. If you really get stuck into this field and if you really know this, you can speak with authority. That's what brings confidence and a sense of value to your visit. You've actually got something positive to give.

JP learned from her experiences with patients.

I think I've probably learned from speaking to patients themselves. With AF, she's had a lot of treatment. She understood it herself and she's been kept up to date from the hospital too. Once I've got the information in front of me, I like to look and see what's maybe going to be expected.

MW had more experience than the other six health visitors, having visited patients with breast cancer for three years. Even so, she sometimes felt confused about different treatments.

I have to confess I get a bit confused about the various treatments, not what the treatment involves but how each tumour is treated. I learn from the patients of course. The general questions I can answer. Anything specific I don't enter into. The doctor should do that. Patients do know a lot. It's important we are seen by them as somebody knowledgeable. I feel more confident than when I started. It took two years for me to feel confident. Colleagues now accept that I know a bit about it.

After their brief education programme and some experience in visiting patients with breast cancer, health visitors felt more confident about their new role.

I think I know a bit more about it now, Before it was just listening and offering to find out more information if they needed it.

It's nice to have some part of your work you feel reasonably informed about. We are jack of all trades and master of none, I always think.

4b Achievement

Health visitors derived a sense of achievement from evidence that their input made a difference to patients' progress. MM, had given intensive support to JL and was beginning to see improvement.

When you see the likes of JL and the response she's had you think maybe you should be visiting them. I don't think I'm going in just for the sake of going in and not achieving anything. It's still progressing.

MW felt that her visits to JJ had been of value, allowing her to express her initial anger about a delayed diagnosis and her dissatisfaction with her breast implant.

I think she (JJ) has benefitted from support. I think my visits to her were of value. I reassured her as far as possible and listened to her.

RA had provided brief but intensive support to AH and had felt that she had helped her with a number of medical and psychological problems. She also felt that she had effectively supported SM and EC.

I think my input to her (AH) was important on all sorts of levels. I thought it was good that she shared the pain. AH, SM and EC all needed support, sometimes information, sometimes just that I'm there.

4c Doing a worthwhile job

All the health visitors considered it worthwhile supporting patients with breast cancer. JP maintained that health visiting had placed too much emphasis on child care, neglecting other important areas.

Unfortunately, till now our management definitely saw children as our future. I haven't always agreed with that. I think this (breast cancer) is a very needy area.

MM agreed.

I think it's been worthwhile, especially regarding JL. I've enjoyed it. I've not found it too difficult.

MW, RA and DL saw breast cancer care as an important part of health visiting.

I see it as very important because I think these people would feel isolated and shocked at the news that they had breast cancer. I see it as an important part of my work and getting it fitted in is important. I enjoy it. MW

I think it's important to visit people with breast cancer. I think it's something that's value increases as you get more involved. RA

I would say it's normal health visiting, an important part of the work. DL

NB saw the work as time consuming but important.

They (patients with breast cancer) have taken up a lot of my time. It's difficult to fit in the new work but I see it as important. I would like to continue doing the visits.

4d Being valued by clients

Health visitors felt their role was valued by most patients with breast cancer and by some professional colleagues and managers. JP felt that AF valued her support.

She'll (AF) ask for help. She intimates, 'You are always welcome.' You've made a relationship of that kind and you feel you couldn't not go.

JP was initially unsure of how helpful she had been to LB.

I said to her (LB) very clearly, 'Do you think it's of benefit me coming along? You sound as though you have got a lot of support around.' She said, 'Oh no. Honestly, I'll look forward to seeing you again.'

Three of DL's patients expressed satisfaction with her support. Initially she felt that she was not providing much support to HM.

At the end of the interview she (HM) said something like she was amazed at how much better she felt or something that made me feel I had done something for her. So I said then, 'I'd like to see you again. How do you feel?' She said, 'That would be fine.'

DL had very enthusiastic affirmation of her worth from one patient.

She (EH) said, 'You are the best thing that happened since it all started.'

RA's patient SM had been through a difficult time with her illness and a bereavement and let her know how much her support was appreciated.

The visit was just at the right time. 'I'm so glad you've come,' she said.

Sometimes health visitors' support was not really wanted. DL's patient, MH, had recently been bereaved of her husband and now had inoperable breast cancer.

I thought I had got on reasonably well but when it came to the end of the visit and I said, 'Shall we arrange another visit?', she was hesitating. I think she keeps her feelings to herself and doesn't share them with anybody, least of all her family. She wasn't enthusiastic about another visit.

4e Status recognition

Two health visitors mentioned the importance of being seen by patients as part of the specialist breast care team.

To be seen as part of the set up is important, not just for ourselves but for clients. Communication with M (Nurse Counsellor) is fine. I also phone the ward fairly regularly for information. MW

After three years doing the job, MW also felt that her breast cancer role was now recognised.

Colleagues see me as the one who does the visiting of the breast cancer patients.

RA felt that she and other health visitors were not yet perceived by patients as being part of the Breast Unit team.

We are outsiders in a way. We're not in the clinics. We're not in the wards. We're not seen there. We're not really part of that network. If EC wanted support I feel she would go to the Hospital people. I would like health visitors who are doing this to be seen as part of the team.

5 Therapeutic effects on patients' identity of professionals' informal support

When professionals appeared to empathise and be concerned with them, patients perceived this as therapeutic. Hospital doctors and GPs tended to focus more exclusively than health visitors on medical problems related to the breast cancer. Some patients said that their GPs had given them emotional support, making themselves available whenever needed, to discuss anxieties. Many patients could not separate their breast cancer problems from other aspects of their lives and sought support for their total situation. CB, a young woman with advanced cancer, was much concerned with the future of her teenage sons in the event of her death. She was desperate to discuss this with the health visitor, nurse counsellor and others. Support which addressed only her medical problems was seen as very inadequate.

Morse *et al.* (1992) claimed that nurses' interactions with patients contained a mixture of formal and informal support which could be therapeutic provided that they were patient centred. The heart of effective nursing support was the nurse's ability to identify with patients' experiences.

The caregiver must be emotionally involved or able to identify with the sufferer. The caregiver must be willing and able to experience or share with the other's suffering in order to respond meaningfully and appropriately to the sufferer. ... The essence of the nurse-patient relationship is the engagement, the identification of the nurse with the patient. p. 811

In many instances, health visitors identified with patients, supporting aspects of their situations not directly related to the illness. AF had periods of depression and had once attempted suicide. She described her life as a failure. Her health visitor, JP sympathised with her situation.

She sees her life as being a failure because that's two marriages that have broken down. To us it seems that she's been terribly, terribly hard done by. Why should she have this as well? She's had a miserable upbringing.

She remains very depressed. She confided that she felt life was not worth living and had attempted to commit suicide by trying to overdose with tablets. As time goes by she won't be nearly so well. I don't feel I could drop off from seeing her.

Some patients discussed long standing family problems with their health visitors. Four patients had stressful relationships with adult children. AF did not get on well with her son and daughter, living at home.

I can let off a bit of steam to her (HV) about that pair and she understands.

JL's daughter caused her anxiety with her marital problems and demands for money.

We (patient and husband) talk to her (HV) about J (daughter). She's away from her husband and got herself a boyfriend. She (HV) says, 'Oh well she's 23. It's time she got on with her own life. You get on with yours and just let her lead her own life.'

EH's daughter was a single parent, sharing her mother's small, overcrowded, house.

She (HV) tried to get my daughter that lives at home with wee Michael, a house.

PY's health visitor, NB, found herself increasingly involved in her family relationship problems.

They (PY's daughters) see me as visiting them as well. In fact very little time is spent talking about her cancer. We had to work through the problems.

EL discussed the effects of her marriage break-up with the health visitor who commented;

She wants a partner in her life. She's lonely. She needed to talk about her love life or lack of it. She really opened up one day. We discussed various leisure pursuits but E does not appear interested in anything. She feels that her social life is very lacking. She misses a meaningful relationship and she's anxious that life is flying by.

Patients described how health visitors had supported them beyond their normal duties. One patient described her health visitor visiting her in her lunch hour, this being her only free time. Occasionally a health visitor was regarded more like a friend than a professional helper. This was AF's perception of her relationship with JP.

She doesn't feel like a health visitor. These people can make you feel so intimidated-officialdom. She doesn't make you feel like that at all. You can have a rare blether and a good moan if you like. She's not there waiting to pick

holes in you. She's not waiting to report back, sort of thing. She's really nice. It's like she's always been there. I've heard about J's family as well. They don't feel like strangers. It's a nice feeling, a comfortable feeling.

Emotional involvement with patients could leave aspects of health visitors' identities exposed and vulnerable. Morse *et al.* (1992) recognised that it was not desirable for caregivers to be constantly in engaged relationships. Other responses were often appropriate and protected the caregiver or were needed by the patient. Health visitor, JP, cut a short a visit to AF as she felt unwell. JP attributed this to the intensity of her involvement in AF's problems.

It's quite involving. You tend to think about it as you come away as well. The visits can take quite some time. In fact A has almost gone through a grief type reaction. I see a big need there. Mind you it would be very draining.

MM (health visitor) became involved in CB's distress. Her diary records;

It was a difficult visit. I found it hard to cope with her distress.

There were compensations in the engaged relationship. The caregiver often received reciprocal support from the patient.

6 Negative effects of professional power on patients' perceptions of support for identity

Power plays a more obvious role in formal than in informal support. The exercise of power by professionals influences their client interactions and the effectiveness of delivered support. Professionals who controlled their relationships with my respondents by dominating interactions and controlling accessibility were seen as unsupportive. By contrast, hospital staff, GPs and health visitors who were openly available to see respondents and discuss anxieties were perceived as very supportive. There were three examples of the exercise of professional power.

6a Professional agenda setting

Adverse effects of power on identity maintenance are evident when professionals' agendas dominate their interactions with clients. Two respondents reported this experience. AF with advanced cancer, feared the prospect of dying. Contrary to her wishes, a GP insisted on discussing her prognosis.

She spoke to me as if I had minutes to go. She said, 'We'll have to rule out something much more serious,' She said, 'You do realise what's wrong with you?'

She started telling me what was wrong. I said, 'I know as much as I want to know. I know that things have progressed but I don't want to know any more.' She insisted on telling me. I think if you don't want to know it shouldn't be forced on you. I'm not ready to know more because I'll go right over the edge. I don't see how her telling me was any help because it frightened the daylight out of me.

IH, was worried about a lumpy breast following radiotherapy. She unsuccessfully sought reassurance.

The radiotherapists didn't notice. It's just their own wee bit they are interested in. Then the doctor says, 'Take your things off.' Then he just goes, 'Oh yes.' I mean, it's ridiculous. Why do we bother because they don't look at the thing. I never felt he asked anything. I thought, 'Hell, I'm going away. I can't get out quickly enough.'

Professionals can also use their power to limit their accessibility to clients, timing interactions with them, making decisions about when to terminate the relationship. However, most of my respondents reported that health visitors were available whenever they needed help.

6b Professional expertise

Professionals can use their expertise either to exercise power over or to empower clients. Respondents reported that health care professionals generally provided information and advice which empowered them to cope. However, although Breast Unit staff encouraged patients' involvement in treatment decisions, some patients felt this was inappropriate. They were more confident about making decisions about cosmetic matters like breast reconstruction. Health visitors helped some patients to explore their feelings about such decisions.

6c Professional gatekeeping

Professionals exercise power through accessing resources, usually knowing more than lay people about available resources and relevant criteria for obtaining them. Health visitors accessed resources for patients drawing their attention to benefits to which they were entitled and helped to secure these.

7 The roles of formal and informal support in maintaining/changing patients' identities at different stages in the illness experience.

The data thus far, makes it evident that both informal and formal support are needed as an individual adjusts to the impact on his/her identity of a serious illness. Medical availability and expertise is required but informal support meets many important needs, maintaining self esteem by demonstrating love and affection, reaffirming various aspects of identity, often providing meaning to life and to life events. To meet patients' changing needs during different stages of the illness, formal and informal support are needed in complementary roles with neither seeking to do what the other does best. These roles will now be examined.

7a Suspicion

Waiting for diagnosis was a very anxious time for respondents. While confirmation of breast cancer temporarily increased their anxiety, it was less stressful than living with uncertainty.

The most awful part was finding the lump and the sheer panic that goes through you. You think, 'I've got cancer. No I haven't. Yes I have.' You argue with yourself. Then you feel panic until someone turns round and says, 'Yes you have it.' Then you get a sort of resigned feeling. I stopped panicking inside and I thought 'Well that's it.' ES

The literature documents the stress of waiting for diagnosis. Lorde (1980) reported her experience with a breast lump;

I knew the horror that I had lived with for a year since my last biopsy had now become a reality and in a sense the reality, however difficult, was easier to deal with than fear. p. 31

7ai Formal support

Most respondents received little professional support at this stage. AW coped with two months wait for a diagnosis by trying to put it out of her mind. She said it would have helped had she been able to talk to a health visitor during the waiting period.

7aii Informal support

Prior to diagnosis, family or friends of some respondents encouraged them not to minimise the possible seriousness of breast cancer symptoms but to report them to their doctors.

7b Diagnosis

Diagnosis was a great shock to most respondents, especially if they had no symptoms of illness. LF reported;

At first, when you are told you have cancer, it's a shock. It takes time for it to get through to you. So you're just walking in a sort of dream at first.

HM had similar feelings.

When they mentioned cancer, I broke down. I went to pieces. I couldn't speak to my husband or anything.

7bi Formal support

At this stage, help came mainly from professionals who defined and provided information about symptoms. Diagnosis, treatment and monitoring of progress made respondents feel less insecure. Doctors and the nurse counsellor provided further information about the size of the tumour, whether it had spread to lymph nodes or other organs and the appropriate treatment. EA found information from a doctor eased her fears.

I asked one of the doctors. All the questions that had been going on in my head, I asked her that day. So I came away feeling an awful lot better.

7bii Informal support

At diagnosis, many respondents compared their situation with other patients to answer questions such as, 'Is my tumour big?' 'Is there hope of recovery?'

My friend told me she had had it. So then I knew what was going to happen. I felt better. She explained what staging meant and what it was all about. So I thought, 'Well it's not a death sentence. Look at her.' ES

The peer group's humour was a buffer against the threat of breast cancer. EA, a nurse, found that humour reduced her anxiety.

We were sitting in the taxi, me and two other ladies and my daughter to get a bone scan. One of the ladies was a widow. We were saying, 'Who can you speak

to at a time like this?' She said, 'Well I prefer to speak to someone on the medical side' and she looked at me and said, 'As for you, you're a nurse, you'd be better speaking to yourself!' You have to laugh.

Peer support helped overcome stigma, decreasing isolation.

There were four of us and we could talk things over together. You keep in touch. You were more or less in for the same thing. You've got something you can all have a wee blether about. MC

7c Treatment

Most patients were pleased once treatment had started as this meant that the disease was being controlled. On starting treatment, AD and ES had less time to worry.

I think it's much harder for families because when you are going through it, you don't have time to think. They do. AD

To be honest you are so busy getting on with it that it's actually worse for the relatives. You're afraid but you're getting on with it. ES

Once EW's treatment had been decided she felt better, especially as the cancer was obviously responding to the chemotherapy.

7ci Formal support

Patients needed advice about treatment problems and feedback about its effectiveness. Where health visitors were not involved, hospital staff supported patients with treatment problems. After her discharge home, RW felt that she could discuss any problems with the hospital staff.

If I'm really worried I know I can go to the Breast Unit. That's a big comfort, I suppose because that's their specialty.

7cii Informal support

Although without medical expertise, respondents' network members provided other forms of support during treatment. Their attitudes and peers' experiences both influenced patients' preference decision making.

I just got a mastectomy. I'm too old for anything else at 45. It's not as if I'm body beautiful. I didn't want to go back into hospital again and I'd heard a couple of times where things had gone wrong. I said to my husband, 'Do you mind if I have the mastectomy and nothing else.' He said, 'No, I'm quite happy with that.' MB

Sometimes peer comparisons made a patient decide against reconstruction if the treatment seemed unpleasant.

When I was there, a lot of them were going through it and they weren't well. One girl said to me, 'If I'd known what it entails I wouldn't have bothered.' My husband couldn't care if I have no breasts. I'm 65. I just felt I was too old to be bothered with it. It's not important to me and it's not important to my husband.
IW

JH's attitude was also influenced negatively by the experiences of fellow patients.

Unfortunately I had met two patients who had had trouble. They had severe infections. I thought, 'I've no option with the mastectomy, but the reconstruction is cosmetic. I can put it off, if I want.'

Respondents often evaluated their coping with treatment with reference to peers. The Breast Unit Sister put AD in touch with another young patient having similar treatment.

Val was very supportive. When I had chemotherapy I felt as if I was going off my head. I was getting up in the night. Val said it was the same for her. Nobody warns you of these things because they don't know. It was really nice to have someone to phone before I was due to have some treatment.

EA had an acquaintance who had been through similar treatment.

She phones every other day and came round and gave me a lot of support because she's been through exactly the same thing. She's back working full time. She coped really well.

Some women reported closely knit networks and/or spiritual beliefs which enabled them to find meaning in the illness experience. MH and her husband were naval missionaries and found the illness had spiritual significance.

M had found that she had got a lump which was a fairly big one. We had only just moved up here and there we were sitting next to a Specialist Unit. Somebody was looking after us and we didn't have any problems or worries. When M came through the door after we had discovered it was malignant, that was a dodgy time. As soon as we told the boss about it, the attitude started to change. Instead of it being an attitude of fear, being a Christian based organisation, we got together and prayed about it. The fear just goes. Mr H

BI recounts her experience.

I believe that the Lord never allows you to have any experience without Him wanting it to be for your good and for His glory. I could be of no assistance to anyone who's had breast cancer if I hadn't had it myself. ... So there's nothing to worry about. I didn't feel I could face the unknown of what lay ahead without knowing that the Lord's people were praying for me.

CN had a lot of supportive friends at the Chinese Church who visited and prayed for her every day.

7d Hospital discharge

Hospital acted as a cocoon for many and, although they wanted to get home, discharge meant facing reality of what had happened, coming to terms with their emotions.

I think you are vulnerable. For one thing you have got a lot of time on your hands. You don't feel fit and well. You are taking it bad because it's the first time in your life you've been off your work. You've just been discharged from hospital. You are beginning to feel a wee bit okay but you are wanting to get some facts together and put it behind you. EA

Going home also meant coping with the expectations of their network members. Lorde (1980) realised that it was the beginning of responding to people as she had before her illness.

Going home to the very people and places that I loved most, at the same time as it was welcome and so desirable, also felt intolerable, like there was an unbearable demand about to be made upon me which I would have to meet. And it was to be made by the people whom I loved and to whom I would have to respond. p. 46

7di Formal support

Patients particularly valued health visitors' availability of after discharge from hospital.

I said to C (HV), 'I think after surgery when you come home your support lines drop off because you're not going every week.' I think that's when C coming can be very beneficial. MW

You are discharged from the hospital and there you are very well looked after. Suddenly you feel you are thrown in the deep end again and you come home. I remember that I couldn't move. I was lying down. At that time you really feel that someone from the medical side who could advise you is helpful, so she (HV) left her number. SL

JL who had breast surgery prior to initiation of the health visiting liaison service, would have appreciated health visiting support after her discharge home.

I think it would be very good then, just someone to hang onto for a wee while. I do remember about six weeks after my mastectomy lying in bed one night and I cried and cried. It was all the pent up emotions after it all, but it took about six weeks before I could cry. It hits you and people are not coming round so much.

7dii Informal support

The understanding and support of their informal networks was essential to respondents adjusting back to normal living. Many patients continued contact with their peers after discharge from hospital. MB's peer group still met regularly, 18 months later.

We meet every couple of months or so. There's A, another M, S, J and there used to be E and myself, but unfortunately E died. I think it brought the rest of us a wee bit closer, you know. We all just made up our minds and said, 'Well E was a wee bit older than we were and maybe she wasn't as able to put up with it.'

Relatives also needed support. MH's husband had a friend who advised him on how best to support his wife.

I phoned up the wife of our previous minister who had had one (mastectomy). She was trying to tell me what she felt she had needed and she was becoming quite personal about it over the phone. She was telling me about the support that I would have to give to M and do it without her noticing. She and her husband had been through it together. She was open about it and down to earth.

A few patients chose not to keep in touch with peers. BI and her husband were missionaries in the armed forces.' She perceived her role as giving rather than receiving support but found it difficult to fulfil this role when ill.

My whole life has been given to trying to think about other people and make friendly contacts and influence them with the Gospel but I just have felt that in that situation that I couldn't handle it. I tried to be friendly and kind to people at the time, but beyond that I didn't feel I could take on the situation.

Due to the treatments they received, EW and CG did not have many opportunities for meeting other patients.

I haven't really got friendly with any of the other patients. Last week when I was at the hospital, a girl came out and she said she'd been attending for two years. She lives two streets away from me. EW

7e Recovery

To recover, respondents needed to put their illness behind them. However, most feared recurrence even some time after treatment ended. BI had had her breast surgery 18 months previously.

Even if you know that hopefully you are clear after your operation, you are still going to have that sneaking feeling in the back of your mind that perhaps it's going to come back or perhaps they have not been 100% honest with you.

ES finished her treatment two years previously.

I'm not going to be the least bit confident until I can turn round and say, 'It's 10 years ago. I'll think then, 'Oh I've been cured.' At the same time I'm just enjoying every day that I've got.

Patients had to adapt to changes in their body images and sexual identities. This often took time. LF was depressed about her body image one year after surgery.

I get depressed just when I look at myself, when you go into the bath, and especially when you're on holiday putting a swimsuit on. One breast is way down here and one breast is up here.

7ei Formal support

Professionals supported patients by monitoring their progress towards recovery. The news that she was making good progress enabled AD to start planning again.

Every time I went in thinking it was just a routine thing, they suddenly said, 'We think it's about time we did this.' So when they said 'Everything's fine. See you in three months,' I was relieved. It's no use planning even a couple of weeks hence because you don't know how you are going to feel. Now I've started making plans for two weeks hence, you know, three weeks maybe. So I suppose I'm getting back to normal life.

Visits to the hospital clinic made respondents feel more secure.

I like the feeling of going and somebody who knows having a look and saying to me 'Everything's all right.' Just the fact that you are going and someone is looking at you means that if anything crops up they're going to catch it quite early. ES

I'd rather go and get examined. It makes me feel happier if I know I'm not missing anything. MB

HM wished that she could be free of clinic appointments but recognised that they were necessary.

I feel better, but I'd be happier if I was clear of the hospital. I don't suppose I'll ever be clear.

Some patients could not be reassured. CN, a young Chinese woman had attended hospital with lumpy breasts for years and now had developed breast cancer. MC finished her breast cancer treatment two years previously but still felt anxious about recurrence whenever she felt unwell. She never mentioned her worries to the clinic doctor.

I've been a wee bit dizzy sometimes. My husband says, 'Did you tell them when you were in hospital?' I say, 'No.' I'm afraid I'm a wee bit of a coward that way. You just don't want them to know other than you're feeling fine.

At some stage respondents needed to discard their patient status and resume their normal roles. They then needed reduced medical input.

I didn't have any health visitor round. I mean hospitals are good places when you need them, but when you are feeling okay you want to forget them if possible.
MC

7eii Informal support

Informal support tends to normalise situations. Many respondents' network members viewed their illness as a short term problem and encouraged them to resume their normal roles. AW's relatives expected a too rapid recovery.

It's pressure, a social pressure. Everybody tells you you look well, which of course I do, but I do get tired and they don't see that. Everybody was saying, 'We must see you.' What can you do when your brother and stepchildren and cousins come? You can't say, 'I don't want to see you.' I tried saying it and they said, 'You mustn't get depressed. Just come along.'

Once AD's husband had returned to work, she had to cope with two small children.

My sister actually cooked the Christmas lunch for us and froze it all and put sticky labels on. All Derek had to do was slice the carrots and he cut his finger. So then he went back to work and I was left to cope all day.

MB's daughters felt that she no longer needed extra help.

I'm back to normal again as far as they are concerned. They say, 'Mum doesn't need any help to do anything.' MB

IW had no time to brood about her illness because of her busy family life.

I don't brood because I've got no time. I've got seven grandchildren who come up and down. I go to see my mother quite regularly. She's ninety and I've got sisters.

Returning to work was another sign of normality. Most working women were anxious to return as soon as possible. ES continued her work as a practice manager during her radiotherapy.

I thought if I could go back to work and everything was normal and I was busy working with other people, I didn't have time to think I was ill.

MB wanted to return to work as a sign of her recovery.

I feel better going to work than being at home. I feel things have got back to normal again.

Returning to work prevented LF from thinking about her illness.

I worked quite soon after it (mastectomy) which I think helped. If you sit in the house after anything like that, it's depressing.

JH felt family pressures had got her back to normal more quickly after her first mastectomy.

The first time I was 15 years younger and the family were young. I had to put a face on things and get on with it. There's no way I could have done that this time, now I'm older. I've kept the job on and I'm glad now. It's an interest.

Uncertainty can be alleviated by contact with someone who has survived the experience. MB found that meeting breast cancer survivors at a self help group was reassuring.

You are meeting people in the same boat as yourself. I'm quite happy to go out to get the company as well as talking about this and that.

IW kept in touch with her peer group nine months after her operation.

I keep in touch with M and M. We started off together and we've more or less kept in touch. We meet each other and we go to the clinic together. We maybe go for lunch. Most of the girls I was in with have all faced up to it.

On the other hand, some women did not want to be in touch with other patients as this reminded them of their illness. AW commented;

I think in some ways it's better to try and put it behind you and forget about it. If you are going to a self help group it's continually bringing it back to your mind.

7f Continued uncertainty/deterioration

Patients with recurrence/advanced disease had to cope with continued uncertainty about the future and deteriorating health. RW, JB and ED worried about prognosis following recurrence. At the same time, they were uncertain whether they wanted to know more, in case they could not cope. This demonstrates the need for sensitive communications with health care professionals.

I'm in limbo land. He (ENT doctor) just looked at my throat and asked some questions. Then he said, 'It's come from your left breast cancer.' I said, 'Pardon, are you talking about a secondary?' He said, 'Yes you've got a little tumour somewhere along the nerve that goes to your vocal cords on the left side.' Nobody has explained what could happen or not. I was just numbed or shattered. RW

It's an uncertain time. We don't know whether things are back to normal or whether there is still something there that shouldn't be there. JB

They try to make your life comfortable and don't hope for too much in the beginning. I have found that I've gone from being a very outgoing type of person to the slightest thing sets me off. I don't know if they told me the full truth if it would help or not. You know that your life is going to be a lot shorter than average. ED

MW had lived with her recurrent breast cancer for 18 years but seemed to be on a downward path.

I find the time between remissions seems to be shorter and shorter. I think that makes you very frightened. I found the last time I didn't take it in. Normally, I would ask questions and ask for something to be explained to me and then I've got it. But I didn't. I was in a daze. I couldn't even remember what the doctor said to me.

Herth (1990) identified seven hope-fostering strategies; interpersonal connectedness, attainable aims, spiritual base, personal attributes, light-heartedness, uplifting memories, affirmation of worth. It is obvious that formal and informal sources are needed to promote these strategies.

7fi Formal support

My respondents with advanced cancer required ongoing medical and nursing support. There were problems of maintaining hope despite a poor prognosis and of controlling distressing symptoms. Availability of support was important. Support from GPs was variable and some patients felt that hospital doctors/nurses had more specialised expertise.

I don't know my GP and he doesn't know me. I don't mind because I feel I'm getting all the help I need from the Breast Unit. I'm going every fortnight (for injection). M (counsellor) said, 'If there's any trouble, you can always see a doctor while you are here.' JL

MW travelled a great distance to attend the Breast Unit and had confidence in the staff's ability to help her through any crisis.

It's a long way to come but to me it's worth it. These girls (nurses) know what they are doing. I think because I know help is there when I need it, it helps me to cope with any little crisis I have alright.

Four of 11 patients with recurrence/advanced cancer in the Initial Survey and all three in the main Macmillan Study had been visited by health visitors, finding this supportive. EM's health visitor called regularly and was 'a great help'. She

encouraged EM to express her feelings and spoke to her husband who was anxious. RW's health visitor was a medically knowledgeable 'outsider' with whom she could discuss her anxieties.

She came after I was told (probable recurrence) by Mr D. She can sit and listen. It's somebody other than a friend, somebody with a bit of knowledge who doesn't laugh at you. I know if I did need help in any way she's got connections.

Only two patients were visited by Macmillan nurses. CC was visited weekly but wished the Macmillan Nurse had been involved earlier. ED's Macmillan Nurse was a family friend.

She is a friend of the family really. It's good now that I've got someone I can ring just for peace of mind.

Treatment enabled women with advanced disease feel in control of their lives. JL was grateful for a reasonable quality of life.

It was diagnosed there in the tummy, a secondary. I had these pills for a while. I've had these jags for about 18 months. It seems to have kept it at bay which is great. I'm grateful to be here all these years.

MW and RW needed to feel that some form of treatment would always be available.

Well I think it was about Easter this year (had chemotherapy) and then I started having problems really about August. You think, 'I'm sure they should have started the treatment ages ago.' I don't think I could actually cope with knowing that something is going on and not having any treatment for it. MW

I'm kind of frightened in case they say, 'Don't take any more Tamoxifen.' I'm getting to rely on it. It's worked for me. RW

7fii Informal support

People with advanced disease can lose many social contacts due to increasing incapacity and fears their illness can arouse in others. ED suffered anxiety attacks since her recurrence. Tension and tiredness made it difficult for her to do the things she enjoyed.

My friends say, 'Do you read? Do you sew?' Well, when you are ill you can't do these things. That's what makes the day so long. Sometimes my nerves are that bad that I can't thread a needle and I haven't got the concentration either. It makes you realise how basic life is.

JB was typical in losing touch with her peer group.

Gradually we lost touch a little bit, because we've all gone different ways. They haven't required any further treatment as far as I know.

RW did not want contact with other patients.

I haven't kept in contact with any other patients. I didn't really feel I could cope with that, it might be difficult if anyone was ill.

ED experienced rejection by patients who felt threatened by her illness.

In hospital I just went up to these two women. They hadn't long had their operations. I said, 'How do you feel?' Then they said, 'Have you had an operation?' I said, 'No.' I had this bag of water I was carrying round (from paracentesis). I said, 'Mine's a hiccup. I had mine five years ago.' This other one said, 'I don't want to hear any more about it.' She said, 'I've had enough of people talking about it.'

Despite their difficulties, some respondents managed to maintain their involvement in family, community and work life. This was mainly due to personal determination. MW was an example.

I'm very, very tired and I do have a busy life which I thoroughly enjoy. This has curtailed it a bit but normally I swim. I'm a member of the drama club. I see people for the district nurses in K. If they have someone in difficulties, I go along and see them at home. I still sing in the choir. My daughter is nursing full time, so I have my little grandson quite a lot too. As you know when you're on early, to have this wee soul popped in the door at 6.30 is not really funny. I think P (daughter) thinks because I'm up and around it's OK.

MW's attitude to her illness was an inspiration to ED who also had advanced cancer.

There was a woman (MW) in the next bed and she was beautifully coiffured. I found out later it was a wig. She took her clothes out and they were all done in tissue. She put out three sets of shoes under the bed. Then she went away. At night time she came back. We found out that she'd had it (breast cancer) for eight years. She was going off every day for radium. She had made it more or less a holiday coming across and seeing all her pals in Edinburgh. She'd go out for dinner. She'd say, 'Oh haven't you seen a prosthesis?' and out would come a false bit. That helped.

JB's family had been helpful since her recurrence but she now wanted to resume her normal roles.

At the beginning I wasn't very good around the house. My husband was doing a lot of the cooking and shopping and that kind of thing. He has angina and he was beginning to find it a bit wearing and tiring. I'm practically back to doing most of the cooking myself.

JL wanted to remain active but had to curtail some activities.

I've always been a very energetic person, doing three or four things a day. Now I curtail them. I really feel that one of the main things is to keep going and have as much interest as you can in things and not give in. I'm pretty involved in the church. I'm an Elder and I do my district and I really enjoy it. I go to the flower arrangement and I enjoy that.

Work was another way of leading a normal life despite having advanced disease. Nine out of 14 women with advanced breast cancer in the Initial Survey and main Macmillan Study were employed. Six managed to continue working despite their illness. RW had mixed feelings about her nursing work.

We have a lot of terminally ill people in the hospital. I don't mind when they are old but we've just lost a 38 year old and a 56 year old with breast cancer. I enjoy work. Sister said, 'We all feel it when we get a patient similar to ourselves. The 38 year old had metastases all over. I was getting to the stage where I was thinking, 'I hope she's not here tonight.' It's not good nursing at all.

Support for sexual identity was as important for patients with advanced disease as for newly diagnosed patients. Retaining her femininity despite having double mastectomies and hair loss was important to MW.

It's very important to have a good wig. To be caught without it can really be shattering. You think 'I can't look so terribly different with no hair.' but oh my goodness you do. Your head looks so wee. It's as if half your personality has been whipped off as well. But wanting to wear a wig and having to be two different things. It's nice to have your own hair. It's part of being feminine isn't it?

ED often felt depressed about her physical appearance. Her husband was supportive.

It's all my false bits. once you take them off you think, 'Oh dear.' Then I lost an awful lot of weight. Then I swelled up in the tummy. I looked like one of those poor little mites you see on TV with the thin arms, thin legs and pot tummy. I don't have the light on when I go to bed. My husband and I had our first little barney for a long time. It sparked off over a dress he wanted me to get. I said, 'Oh what's the point? I've got that much in my wardrobe that I can't wear because I'm going up and down in size.' I've always put this brave face on. Just now and again you can't. I think it's only you and your husband that has to accept it and mine never showed any repugnance.

JL was also depressed about her appearance.

I don't look at my mastectomy very much. If I'm having a bath and I look up I think, 'Oh my goodness, you do look awful.' I'm so thin and scraggy looking. My husband has been very kindly and gentle with me. We've come to terms with it. We're a bit past a sex life. He's not got the energy you know. He says, 'If you had seen yourself when you were really ill, you're a miracle now.'

Summary

This chapter's data indicated that professional support played an important part in maintaining respondents' identities during illness, especially during transitions from one status to another, for example, at diagnosis.

Professional expertise helped respondents to appraise the nature and seriousness of the crisis. Health visitors informed patients about treatment, assessed respondents' concerns about their progress and tailored their support to meet individuals' needs. Professionals increased respondents' coping by their perceived availability, help in clarifying problems, making treatment decisions and dealing with negative emotions. Health visitors also provided practical support.

Breast cancer undermined respondents' sense of permanence and security. They needed to express these feelings openly and put their cancer experience into perspective. Health visitors helped respondents to do this, often filling the role of outsiders to whom patients could express their deeper fears while protecting their families from anxiety. Regular monitoring of their health after treatment had ceased, also reassured respondents.

In line with previous research, almost a third of respondents reported periods of depression which seemed to result from their lack of control over their situation. Professionals encouraged patients to regain control by involving them in treatment decisions. However, while a few patients readily accepted this opportunity, most wanted the decision to be guided by the doctors. A few wanted to delegate decision making completely to medical staff. Health visitors helped respondents to evaluate cosmetic, treatment decisions.

Health visitors helped patients to explore feelings about their body image and sexuality after breast cancer treatments. Discussing effects on their sexual relationships required sensitivity.

Health visitors supported respondents' relationships and thus, indirectly, their identities. In 14 instances, they spoke to other network members, for example, children, partners when there were problems or anxieties.

Professionals, like patients, needed to maintain and enhance their identities. Competence, achievement, doing a worthwhile job, being valued by clients and

status recognition were important factors in their professional self images. However, their competence was threatened initially by their inexperience.

Professionals' informal support alongside a more formal approach was therapeutic to patients. Respondents wanted health visitors to empathise with their total situation, not just the medical aspects. Negative effects of professional power on patients' perceptions of support were seen in a few instances of professional agenda setting.

Formal and informal support had different but complementary roles in maintaining patients' identities at different stages of the illness.

There was a lack of professional support during the period of waiting for diagnosis. At diagnosis, help came mainly from professionals in providing information but peers provided comparison support and companionship.

During treatment, professionals invited participation in decision making, advised on problems and gave feedback about effectiveness. Informal help with cosmetic, treatment decisions was important, especially from partners. Respondents evaluated coping with reference to peers.

On hospital discharge, health visitors' availability helped patients come to terms with emotions and cope with ongoing treatment. Informal support from network members was vital in enabling respondents to adjust to normal living.

During recovery, professionals continued to monitor patients' progress, while reducing their input to promote their independence. Important to recovery were encouragement from network members to return to normal family and work roles and contact with breast cancer survivors.

In cases of recurrence or deterioration, patients were often uncertain of how much information they wanted from professionals. The challenge for professionals was to maintain hope, provide availability and continuity of care and have a treatment plan to give patients a feeling of control. Some of these patients had suffered a loss of social contacts but others were supported by involvement in their local communities, homemaker roles, and paid work.

Chapter Seven

Discussion and Recommendations

What was the research about?

At the outset of this research, I discussed problems posed by the meaning of social support. Words are often used too loosely and social support means a variety of things to different people. To clarify this puzzling but important concept, I conducted a qualitative study to gain insight into perceptions of the essence of social support among women with breast cancer and their health visitors. Initially, I asked myself whether it was possible to define the nature of support by using phenomenological research methods or if this was a philosophical question, answerable only by using philosophical methods. Having decided that the former approach was valid for reasons explained in the literature review, I asked myself, 'If social support can be defined, what are the implications of that definition for sociological theory, for care of women with breast cancer and for nursing?' Interview transcripts of women with breast cancer and health visitors provided the raw data on which analysis was based. After using grounded theory to extract themes from the interviews, I discovered that the connecting theme underlying patients' perceived problems was the threat to aspects of their identities posed by their illness. I hypothesised that the essence of social support was maintaining or changing these threatened aspects of women's identities. I used discourse analysis to reanalyse my data, searching for evidence in patients' and health visitors' statements to support this insight. Since social support operates in a great variety of situations, further research should be conducted, exploring perspectives of different people in different circumstances.

In this discussion, I will focus on the implications of this meaning of social support from three aspects ;

- 1 Sociology
- 2 Breast cancer care
- 3 Nursing and health visiting

1 Sociology

Respondents perceived social support to be actions or attitudes from formal or informal sources which helped them to maintain their established identities or make changes to their identities in response to threats associated with breast cancer.

My data provided evidence of the role of social support in *maintaining* identity. Many respondents wanted to 'get back to normal' in their relationships and in their work. More long term follow up would have revealed whether this return to normality was complete or pertaining only to aspects of their lives.

There was also evidence of the role of social support in helping respondents to make *changes* in their identities, adapting their self perceptions to their changed circumstances. They needed support to accept these identity changes. For example, most respondents no longer felt the same confidence in their future because of the potential threat of recurrence of breast cancer. However, the example of peers who had recovered from the disease and regular medical monitoring helped them to cope with a future which was now more uncertain than they had previously supposed. Some respondents reported that the support that they had received from significant others during their illness had changed these relationships for the better. Again, more long term follow up would have explored more fully, the role of social support in changing identity.

Respondents' negative statements about lack of support were treated as indicators of the support they had hoped to receive but did not.

1a Processes of affirmation and recognition of social identity

Some sociologists like Hirsh (1981) have observed that social support maintains people's identities through processes of affirmation and recognition from their social network members. My research explored some of these processes of affirmation and recognition. An aspect of informal support often mentioned in the literature is its variety. This was very important in a crisis situation where many different kinds of support are needed. Respondents identified seven main types of informal support.

Types of informal support

- i Emotional support
- ii Companionship

- iii Practical help
- iv Opportunity for confiding
- v Experiential support
- vi Sexual identity support
- vii Advocacy

All of these support types were perceived by respondents as helping them to maintain their social identities in the face of threats from their breast cancer. Partners offered all types apart from experiential support, and had the primary role in supporting women's sexual identity. It was not surprising to find that most women with partners found these to be their main support. Single, widowed and divorced women found their major supports in close relatives. Friends were important sources of support, providing most of the different types, except practical help and sexual identity support. On the other hand, neighbours confined themselves to giving emotional support, spending more time with the patients and offering practical help.

1ai Emotional support

I defined emotional support as expressions of concern and love. Emotional support could vary in degree from a phone call to say, 'I'm thinking of you' to the deep affection shown by close family members. It reassured respondents that people were concerned about them, thus affirming these relationships and strengthening bonds.

1aii Companionship

Respondents spoke of the support they received when others spent time with them. I have called this support type 'companionship' to emphasise its key element of not being alone. Sometimes it involved sharing interests. Once discharged from the supportive hospital environment, many women felt rather isolated. They still needed time to come to terms with what had happened to them. Although well enough to be at home they had not recovered sufficiently to resume all their normal tasks and roles. Often partners had returned to work and the women felt a need for someone with whom to spend time and to talk to about their feelings. This role was most often filled by friends.

1aiii Practical help

Fulfilment of social roles is important in maintaining identity. Respondents appreciated temporary help from their network members in fulfilling roles which they found difficult to perform themselves because of surgery or other treatments. This kind of support had to be given tactfully and withdrawn when appropriate or it was seen as undermining their identities.

1aiv Opportunity for confiding

Most (80%) respondents commented on the support they received from confiding in someone during their illness. Confiding usually involved revealing their deep anxieties and therefore implied great trust in the confidant. Indeed, patients described feeling that it was 'safe enough' to confide in someone. Husbands, friends and fellow patients were most frequently confidants. Some respondents said that confiding alleviated their anxieties and helped to feel less depressed about their situation thus echoing the findings of Brown and Harris (1978) that confiding increased a sense of self worth and reduce the risk of depression.

1av Experiential support

Experiential support affirmed respondents' identities in unique and important ways. It provided opportunities for comparison with others 'in the same boat'. Sometimes respondents made downward comparisons with those perceived as being worse off than themselves. Frequently, they made upward comparisons with women who had apparently overcome their disease. Most women received support from fellow patients who helped them overcome the stigma of having cancer by decreasing the sense of isolation and differentness. Two thirds of the women had experiential support from friends or relatives who had themselves been treated for and recovered from breast cancer.

1avi Sexual identity support

This form of affirmation was particularly important for respondents because their body images and sexual identities had been threatened by breast cancer and breast surgery. Women reported being helped by partners' reassurances that breast cancer and breast surgery would not adversely affect their relationships. Husbands/partners played a key part in affirming women's sexual identities.

Advocacy supports identity by speaking for someone when, for some reason, they are unable to do this for themselves. Relatives' or friends' offers to accompany respondents to breast clinic appointments were described as an important source of support, as respondents often felt very vulnerable on these occasions and unable to ask questions or to remember what doctors had said. They described a feeling of facing a threatening situation together.

1b Supporting changes in self perception by initiating changes in social network membership

My findings agree with those of Hirsh (1981) who noted that attempts to build new social identities to cope with life changes or transitions, may require people to initiate changes in their networks.

Respondents actively constructed support for changes in their self perceptions. Many *reactivated* their relationships with friends and acquaintances who had recovered from breast cancer. Some dormant relationships were reactivated when patients decided to reveal their illness. These relationships were often with women who could act as role models for their future selves, being a stage further along the road to recovery. However, sometimes patients were unaware that a friend or acquaintance had had breast cancer and were surprised to make this discovery.

Most women also formed *new* supportive relationships. Many chose to confide in their peers. Fellow patients were 'in the same boat' and could affirm that they were coping and that their feelings about their situation were shared by others. A few patients chose not to confide in peers because possible demands of the latter for reciprocal support, posed a threat to their own identities.

1c Support as exchange of resources-reciprocal identity maintenance

At the outset of the research, I was interested in feelings and expectations involved in the processes of giving and receiving social support. Respondents' comments indicated that social support was reciprocal, not a one way process in which they were passive. Their desire to reciprocate the identity support offered to them was seen in three ways;

- i early resumption of their normal roles

- ii protecting their network members from stress
- iii offering support to others

1ci Early resumption of normal roles

Both respondents and their network members were anxious to resume their normal roles within the family and at work as soon as possible, once the acute phase of the illness had passed. This was an indication of the women's desire to reciprocate the support they had received.

1cii Protecting network members from stress

One way in which respondents protected their network members' identities was in concealing their deepest fears about their breast cancer. They did this, for example, by maintaining a cheerful facade to protect those close to them from anxiety.

1ciii Offering support to others

Many respondents spoke of offering support to others, particularly fellow patients.

Respondents perceived reciprocation of support to be important, thus agreeing with previous research findings. However, this did not imply that they perceived a need for equality in the amount of support given and received, as is assumed in 'exchange theories' of social support. By 'getting back to normal' most respondents meant restoring their relationships and roles to what they had been before the illness, rather than to any idea of evenness in participation and identity support. Their roles as mothers, sisters, wives, housewives and their occupational roles were important in their self concepts. Indeed, getting back to work was seen by many of the women as an important indicator of their recovery and a boost to their self esteem. Respondents had expected and accepted temporary support from family members in fulfilling their homemaker roles. However, when a few relatives were overprotective in this regard, respondents resented this. These findings agree with those of Mead (1934) and Durkheim (1970) who emphasised the importance of social roles and statuses in maintaining individuals' identities. They also accord with Northouse's and Swain's (1987) findings that a great concern of women with breast cancer was whether they would return to previous lifestyles.

In noting the value of roles in supporting identity and social integration, Mead (1934) and Durkheim (1970) did not discuss the strains which could be generated by

strong identification with certain roles and which were experienced by some women in their various family roles.

Respondents' relationships required attention from, as well as offering attention to them. During the acute stages of the illness, the flow of support was mainly from network members to patients and 46% of women described predominantly supportive social networks. Initially, their sick role put the women into a dependent position within their networks. They were temporarily unable, physically or emotionally, to fulfil their normal roles at work and at home. They needed time to come to terms with their feelings about the illness. This change in status elicited behaviour changes in their network members, the majority offering extra support.

? 46%

However, while there was an overall increase in network members' supportive behaviours after the breast cancer diagnosis, over half the women had network members who required support from them at this stressful time and whose social networks therefore offered a mixture of support and strain. One patient had a predominantly stressful network which offered her little support.

Sometimes network members were unable to offer support to respondents because they were ill and needing support themselves. However, most negative behaviour seemed to result from network members perceiving the women's illness as in some way threatening their own identities. A few relationships were lost altogether because of this.

1d Quantity of relationships and identity maintenance and change

Respondents identified an important reason why having a larger social network might be more supportive than having a smaller one. In the crisis of illness, they needed and sought different types of support from various sources to maintain and make changes to their identities. These could not usually be found within a few relationships, even if close, as the following examples show.

- 1 When anxious, respondents did not always choose their partners as confidants. Close friends were chosen almost as often because of the need of some patients to protect from anxiety those closest to them.
- 2 Respondents sought experiential support from those who had themselves had breast cancer, knowing that the latter would understand their feelings about the disease.

- 3 Many patients spoke of the need to have people who would spend time with them and with whom they could talk. It was friends who often fulfilled this role.

1e Quality of relationships and identity maintenance

As previous research has indicated, quality of relationships was very important to well-being. The social intimacy provide by their close relationships provided support for many aspects of respondents' identities and these relationships were in themselves part of their identities.

1f Social identity and Limits of Support

I found links between social identity and limits of support. Data indicated that the support individuals can give to others can be limited by two factors.

- i Perceived threat to their own identities
- ii Close involvement (identification) of helper with helpee

1fi Perceived threat to own identity

Formal and informal helpers may perceive a situation as threatening their own identities, making them want to distance themselves from a person requiring support.

Respondents reported instances where their network members perceived breast cancer as a threat to their own identities and were consequently unable to give them support. There were also a few instances of respondents themselves being reluctant to keep in contact with fellow patients in case the latter relapsed and thus threatened their own security.

Professional carers are not immune to perceiving threats to their identities which inhibit their support of clients. Aspects of health visitors' professional identities were threatened or supported in their interactions with respondents. For example, their perceptions of themselves as competent professionals were initially threatened by their lack of knowledge about breast cancer care and their perception that patients expected them to be 'expert' in this area.

1fii Close involvement of helper with client

The second factor which may limit the support one person can give to another is close involvement or identification of the carer with client so that his/her sufferings become the carer's. Health visitors became closely involved with some respondents, being regarded by the latter more as friends than professional carers. They found such involvement was rewarding, thus agreeing with the views of Morse *et al.* (1992) who claimed that relationships which 'embodied the sufferer's experience' were more rewarding for the caregiver than more detached relationships. However, health visitors found these close relationships emotionally draining and there were limits to how many such patients they could support at any one time. This indicates that there was some risk of burn out unless health visitors' case loads were balanced by having other clients needing less intensive support. Morse *et al.*'s (1992) claim that emotional involvement with the sufferer, because rewarding, would reduce the risk of burn out in the caregiver, should be treated with caution.

2 Breast cancer care

The sociological concepts already discussed in relation to social support become specific in the context of the breast cancer experience.

2a Crises of identity associated with the breast cancer experience

Although respondents had problems which were common to many diseases, these presented particular aspects in breast cancer, for example, the continuing risk of recurrence over many years, the threat to sexual identity. Respondents indicated that they were faced with six threats to their identities associated with breast cancer.

2ai Mortality vs Permanence

Prior to their illness, respondents had been able to plan for the future with some degree of confidence. Initially, the perceived threat of death from breast cancer undermined their sense of security and ability to plan for the future. This insecurity persisted even in women who had finished their treatment for breast cancer several years previously. Contact with other patients and with friends and acquaintances who had had recurrence of breast cancer increased their awareness that it was a continuing risk.

2a ii Sickness vs health

Prior to their illness most respondents had considered themselves healthy, in that they had no signs of serious disease. Respondents expressed the desire to cast off their sick roles and to get 'back to normal'. However, they no longer had the same confidence in their health as they had had prior to the illness, since long term medical follow-up reminded them of their vulnerability. Feeling in control of their bodies was an important part of their identities yet, as the cause of their breast cancer was unknown and preventive measures uncertain, it was difficult for them to feel that they had control over their health. They did not know what steps to take to prevent the recurrence of their breast cancer.

2a iii Dependence vs Autonomy

Prior to their illness, most respondents had thought of themselves as competent and independent people. Now their disease made them feel uncertain of their physical and psychological coping abilities. The illness and its treatment imposed physical limitations although these were usually temporary.

2a iv Stigma and isolation vs normality and integration

Prior to their illness the women had regarded themselves as 'normal' people, integrated into their families and communities. Having breast cancer made the women feel powerless and unsure of their statuses, especially when they were subjected to others' negative expectations and labelling. Many reported that cancer carried the same frightening connotations for them that were held in society generally. Initially, they felt very much alone and isolated by their disease.

2a v Damaged sexuality vs Normal sexuality

In varying degrees, breast cancer and breast surgery threatened the sexual identities of most respondents and they felt a loss of attractiveness. However, their concern about having cancer predominated over concerns about sexuality.

2a vi Impaired relationships vs Normal relationships

Prior to their illness most respondents had felt secure in their relationships with their network members. Close relationships form part of a person's identity and give feelings of security and competence. After diagnosis, they felt less confident in

their relationships and their roles as wives, mothers, friends and workers. Despite longstanding, close relationships with their partners, many of the women worried about the latter's possible reactions to their changed body images. Respondents reported needing to feel that their most significant relationships would not be adversely affected by their illness.

2b Critical stages for redefining identity during the illness experience

During the illness, these identity threats formed a series of crises which respondents had to negotiate to reach for recovery. Coping with the crises involved a re-evaluation of self and an acceptance of change of self. Failure to cope with the crises meant that some aspects of respondents' identities remained under threat and the crisis was unresolved. My findings have some similarity with Erikson's (1965) description of 'ego qualities' which emerge from critical periods of the individual's development through the life cycle. Erikson's ego qualities were;

... criteria (identity is one) by which the individual demonstrates that his ego, at a given stage, is strong enough to integrate the timetable of the organism with the structure of social institutions. p. 238

Erikson (1965) described these crises in individual development as a series of alternative basic attitudes. However, in my research, respondents had to cope with several threats to their identities simultaneously.

Although most respondents coped well with their illness and were beginning to get back to normal living, six months to a year after treatment, aspects of their identities often remained under threat. Many patients still talked about their fears of recurrence, six spoke of dissatisfaction or lack of confidence in their body image and sexuality. Two patients did not feel confident enough to go out of their homes, thus making them socially isolated. Data from the Pilot Study and Home Interviews, revealed examples of unresolved identity crises among patients who had had their treatment several years previously. One patient in the Pilot Study was still very preoccupied with the effects of mastectomy and breast reconstruction on her body image and sexuality three years later, to the extent that it severely limited her social life.

2c Self acceptance as an aspect of health

Health, like social support, is a difficult concept to define. Although absence of disease was an important indication of respondents' recovery, they also spoke of

other signs of health such as 'getting back to normal', 'getting on with my life', 'putting it behind me', 'being back at work', 'valuing my family more' and spending more time together. This agrees with Woods^{et al's} (1988) research in to women's images of health which, in addition to absence of illness, included the following;

actualising self, practising healthy life ways, self concept, body image, social involvement, fitness, cognitive function, positive mood and harmony. p. 40

They had to put their illness behind them while accepting their new vulnerable status as people whose health needed to be monitored for many years to come.

3 Nursing and health visiting

Respondents indicated the importance of both formal and informal support in helping them negotiate successfully, critical stages in their breast cancer experience.

Professional health care workers were perceived to be an important part of women's social support networks during the illness. However, formal and informal sources differed in their methods of providing support. Whereas network members mainly relied on their personal knowledge of and relationships with respondents to help the latter, professional health careworkers used their medical expertise and experience with other patients.

3a Patients' perceptions of formal support

Respondents identified medical knowledge and experience as being particularly important in helping them to *appraise* the implications of the breast cancer diagnosis and to help them *cope* with the illness and its treatment.

3ai Appraisal support

This was a distinguishing aspect of professional support. Respondents received from doctors, nurses and health visitors, diagnostic, informational and psychological support which enabled them to appraise the nature, seriousness and immediacy of the threat of breast cancer to their well being.

3aii Softening or removing the threat

Professional health care workers had an important role in providing information about breast cancer and its treatment and in giving treatment. This helped to soften the threat posed by breast cancer.

3aiii Support for coping

Respondents indicated that their uncertainty and anxiety was reduced and their coping ability increased by the availability of professional health care workers to support them. In particular, health visitors were perceived to be accessible and approachable and able to provide them with personalised support.

3b Health visitors' perceptions of their support to patients

The concept of support has had a non specific meaning for nurses. In this research, health visitors perceived their support for women with breast cancer to consist of the following.

3bi Appraisal support

Health visitors saw themselves as providing appraisal support by helping patients to assess the significance of any problems they had after discharge home from hospital.

3bii Medical information and advice

Health visitors recognised that patients looked to them for medical information and advice and that some expertise in this area was necessary to assist patients' coping.

3biii Support for coping (availability, psychological support, practical support)

Health visitors saw *availability* as an important part of helping patients to *cope* but health visitor's and patients' comments indicated that availability was patient directed in only 54% of cases, that is, it was perceived by the women to be available whenever they wanted it. In other cases, the health visitor decided when to make herself available to patients.

Health visitors encouraged patients to explore and express their feelings and attitudes towards their situation. Health visitors considered their ability to give

patients psychological support to be the most important skill for good practice. In a questionnaire administered at the outset of the research and after 8 months experience, their perceptions of the importance of their ability to give psychological support to patients with breast cancer increased from 4.0 to 4.8 on a 0-5 scale (Appendix 8).

Health visitors discussed with patients and assessed how they were *coping* and perceived themselves as providing *practical support* to help patients cope. This took the form of financial advice, organising transport to hospital for treatments and obtaining aids.

3biv Family support

While health visitors maintained that patients were the focus of their attentions, they also perceived themselves to be family visitors, providing *family support*. In some cases this was direct support to patients' network members to enable them to cope better with the patient's illness. In 40% of cases, health visitors had some contact with other members of the patients' social networks because the latter were present during one or more of the visits. Secondly, health visitors provided support to patients by acting as their confidantes when they felt unable to share anxieties about themselves or their network members with the latter.

3bv Maintaining patients' identities

Health visitors did not explicitly mention assessing and maintaining threatened aspects of their patients' identities. Their future recognition of this process in their interactions with clients should lead them to give it more salience, thus increasing the effectiveness of their support. However, patients' and health visitors' comments indicated that this was implicit in their support.

3bvi Mortality/permanence-discussing aspirations, future plans

One of the threats to respondents' identities was to their sense of permanence and having a future. Health visitors discussed patients' hopes for their future and encouraged them to make plans.

3bvii Sickness/health-promoting a healthy self image

Because respondents faced uncertainty about their future health, it was important that they began to put their breast cancer experience into the background. Health visitors encouraged patients so far as possible to think of themselves as well women and to perceive the completion of medical treatment as a significant milestone en route to recovery.

3bviii Dependence/autonomy-providing opportunities for self determination

One of the effects of *having* breast cancer was to undermine respondents' perceptions of independence and autonomy. Although invited by medical staff to participate in decisions about their treatment, their vulnerable position as sick people with limited medical knowledge often restricted the extent to which they wanted to be involved in such decisions, especially when they thought that these might influence their prognosis. They generally felt more able to make 'preference decisions' about cosmetic surgery. While health visitors did not help the women to make 'life and death decisions' about treatment, they sometimes helped them to make 'preference decisions' about whether to have a breast reconstruction. Medical and nursing staff were perceived to be supportive when they tailored medical information and responsibilities in decision making about treatment to women's individual requirements.

Learning new skills develops a positive self image. Respondents had to cope with a new body image, wearing a prosthesis, adapting clothing and swimwear to disguise the effects of surgery. Those receiving chemotherapy had to cope temporarily with caring for and wearing a wig. They needed support from health visitors and hospital nurses to acquire these skills.

3bix Stigma and isolation/social integration-promoting self acceptance/self confidence

Respondents had initially felt stigmatised and isolated by their breast cancer. It can be difficult for people who have been disfigured to accept themselves as they are because the pressures of society encourage them towards an ideal self that would be more acceptable to society. For example, should a woman with mastectomy have breast reconstruction because she feels that this would make her more socially acceptable? It is important that people feel that the self is more than external appearance.

3bx Damaged sexuality/normal sexuality

Health visitors encouraged respondents to discuss their feelings about body image and sexuality, asking whether they had looked at the scar and to describe their feelings about it. They helped them to develop a positive body image by attention to prosthesis fitting. Health visitors also discussed with some of the women, their anxieties about their sexual relationships

3bxi Impaired relationships/normal relationships-discussing patients' perceptions of others attitudes

Respondents saw their breast cancer as a threat to their relationships and they were anxious that their significant others should respond to them with the same love, acceptance and respect that they had experienced before the illness. Health visitors explored patients' perceptions of others attitudes towards them and helped to promote normal relationships between patients and their significant others by giving the latter information and support.

3c Roles of formal (nursing) and informal support at different stages of the illness experience in maintaining and transforming patients' identities

Respondents indicated that timing of support was important. It was not effective if given after a crisis had passed. For example, when a health visitor was unable to visit a patient soon after her discharge from hospital, her later offer of support was not appreciated by the patient who reported that she had worked through her anxieties and did not want to discuss them again.

When respondents passed from one status to another, for example, at diagnosis or on discharge from hospital, their identities were redefined by others and by themselves. It was at these times when they particularly needed both formal and informal support to avoid negative and encourage positive self concepts. In an earlier research study of the support of relatives of terminally ill patients (Lugton 1986), I found that the presumed finality of admission to a hospice was a major concern to both patients and relatives, being perceived as a 'rite of passage' which conferred on those admitted the status of 'the dying' in a unique way. Professional support was very necessary at this time.

The experience and expertise of health care professionals was particularly important in supporting respondents at diagnosis, during treatment, during

convalescence and in some cases, at recurrence. Support from informal sources was important throughout the illness in maintaining women's identities as wives, mothers, sisters etc. but it had a special role in promoting recovery and returning respondents to normal roles and relationships.

3ci Suspicion (prediagnosis)

Respondents indicated that this was a period of great anxiety for them when they received little professional support. Sometimes it was three or four weeks from suspecting a breast abnormality to attending the hospital diagnostic clinic. This finding agrees with that of Jamison *et al.* (1978) who noted that patients with mastectomy reported that the period after discovering a breast lump and before biopsy was very stressful but most women had little opportunity to discuss their feelings. Is it possible to provide support in anticipation of a stressful event such as the diagnosis of breast cancer? My respondents indicated that having a professional person to talk to at this time would have helped them greatly.

Network members played an important role in persuading some respondents to report abnormal symptoms to their doctors.

3cii Diagnosis

At diagnosis, respondents faced a transition from the role of 'well woman' to that of 'patient' with a life threatening illness. Diagnosis usually coincided with admission to hospital and a consequent loss of autonomy and feeling of powerlessness. To negotiate the transition, respondents sought appraisal support from health care workers.. When health visitors were able to visit patients around the time of diagnosis, rather than after surgery, this was particularly appreciated. Health visitors early, pre-surgical contact with patients with large tumours helped to build up supportive relationships.

3ciii Treatment

During treatment respondents experienced threats to their sexual identities from surgery, chemotherapy and hormone therapy. Again this was a time of feeling dependent on medical expertise, since treatments could affect prognosis. Medical information was important in enabling respondents to make treatment decisions and for their coping during treatment. As adjuvant treatments were conducted on an out-patient basis, health visitors' role in enabling patients to cope with these was

appreciated. Respondents often needed information and advice about medical problems and support to assess the significance of these problems. They sometimes needed practical support from health visitors to help them cope.

Informal support was important throughout treatment. Network members played a role in discussing treatment options, especially cosmetic surgery, with the patient. Experiential support from relatives and friends and peers who had had breast cancer assisted patients' coping. The latter acted as role models for coping, providing opportunities for comparison.

3civ Discharge home

On discharge home, respondents made a partial transition from the role of patient to well woman. They had still to receive several weeks of adjuvant treatments on an out-patient basis. This was a time when many respondents felt vulnerable. In hospital they had had information, advice and practical support from the medical and nursing team and experiential support from fellow patients. They had been absorbed in recovering from the immediate effects of breast surgery and in coping with their treatments. On discharge home, they had to come to terms with psychological effects of the cancer diagnosis and of breast surgery. They were still redefining their identities when it was time to leave the relatively private world of the hospital and test acceptance of these identities in their families, communities and occupational worlds. At this stage, respondents needed support from both formal and informal sources. Many mentioned the availability of health visitors as being important in allaying their anxieties. A quarter of the women mentioned the benefit of expressing their deeper worries to health visitors because the latter were perceived as being 'outside' their normal social relationships and therefore detached from the patterns of obligations and expectations inherent within these relationships. Network members themselves needed support from professional staff. Most respondents (30) indicated that health visitors' support had been important to their coping. Some women (17) needed limited health visiting support to help them to cope with a particular crisis, for example, dissatisfaction with breast reconstruction, having to return to hospital for further tumour excision. Others (13) had severe medical and psychosocial problems requiring more protracted health visiting support.

3cv Recovery

Recovery was not a clearly defined transition. There was no point at which respondents were told that they had fully recovered from their illness. On the contrary, women were aware that they would need to attend the Breast Unit for monitoring for many years to come. This lack of a clear transition from sickness to health was difficult for respondents to cope with and they tended to substitute their own indicators of recovery such as returning to work, resuming their normal roles at home, offering support to others currently having treatment for breast cancer.

Hospital medical staff played an important role in helping respondents to put their illness into the background by regular check-ups which gave women a feeling of security. Health visitors stopped visiting once women no longer seemed to need their help but encouraged patients to contact them again should the need arise.

Informal support from close relationships was often most effective in assisting patients in the transition to recovery. With a few exceptions, relatives and friends encouraged them to 'get back to normal' and to resume their former roles at home and work. They apparently regarded respondents as well women again. Were they less aware than respondents of the threat of recurrence?

3cvi Recurrence

Apart from the breast cancer diagnosis, fear of recurrence was the anxiety most frequently mentioned by respondents. Later, three women did, in fact, have recurrence of their breast cancer and had to cope with a transition from having curable to incurable disease. They needed to maintain a sense of control over life.

The presence of health visitors, already known to these patients, was particularly appreciated at this stressful time because they needed help to make a fresh appraisal of their situations, without losing hope of symptom relief and reasonable quality of remaining life. Health visitors were able to offer some support to their relatives as this was also a time of great stress for them.

3cvii Advanced disease and terminal illness

Respondents with advanced disease struggled to remain involved with family and community life. Some (4) continued working for as long as possible. It was difficult

for those with advanced disease to acknowledge that they could now receive only palliative care because they attended a Unit where patients were receiving curative treatment.

Professional support was very important at this stage of the disease. However, respondents now had less contact with hospital medical and nursing staff except when attending clinics. GPs varied in the amount and quality of support they gave and had health visitors not been visiting, respondents would have had little community nursing support, unless requiring practical help from district nurses. Only one patient received support from a Macmillan nurse, the latter being an acquaintance who offered to visit her.

Informal support was also vital for patients with advanced disease. However, this was a stressful time for relatives and in two cases they were unable to give the necessary support. Most of these women were no longer in contact with fellow patients and one experienced rejection by other patients when in hospital, the latter not wanting to talk to her.

3d The role of nurses in maintaining and building informal support for patients

Informal support from their significant others was vital for respondents' coping with and recovery from breast cancer. Instead of 'an exclusive reliance on professional frames of reference' (Froland *et al.* 1983), my data showed that nurses should aim to help patients maintain and if necessary, create their own informal support during illness. Nurses and health visitors encouraged informal support for respondents in the following ways.

- i Assessing patients informal support needs
- ii Preserving support (minimising network disruption, supporting network members)
- iii Encouraging supply of missing aspects of support (experiential support through peers)

3di Assessing patients' informal support needs

Health visitors assessed the support provided by respondents' network members using a Domiciliary Assessment Form (Appendix 6). They asked patients about the practical and emotional support they were receiving from their key relationships. They also explored, when possible, respondents' sexual relationship with

husbands/partners since the breast cancer diagnosis. Health visitors drew network diagrams for each of the patients they visited, these indicating the reactions (positive and negative) of network members to patients' illness and enabling health visitors to assess which aspects of support were not being provided informally. Health visitors were then in a position to ask, 'Can existing network members can be assisted to provide the kind of support that is needed?'

3dii Preserving informal support (minimising network disruption, supporting network members)

Respondents sometimes needed help in removing communication barriers between themselves and their network members. Some women were reluctant to express their concerns about their illness to those closest to them, wanting to protect the latter from anxiety. They needed encouragement to talk to relatives about their feelings or opportunities to express their fears about their prognosis to health visitors who were not emotionally involved. Even within apparently good relationships, barriers existed. Some women described being very worried about how their breast surgery would affect their relationships with their partners and found relief in expressing these anxieties initially, to the health visitor or to fellow patients who could assure them that such feelings were normal. Sometimes respondents needed guidance from health visitors on how incapacitated they would be after breast surgery, to encourage them to accept the temporary practical assistance they needed from their network members. They needed professional 'permission' to accept their transitory state of dependence on others.

Respondents' network members also created barriers preventing them from supporting patients effectively. When possible, health visitors helped network members to discuss their feelings about the illness and how this might be inhibiting their support of the patient. Respondents' partners sometimes wanted information from health visitors to enable them to better understand what patients were experiencing. A few also wanted to be present during the health visitor's visit to enable them to hear their wives/partner's worries at first hand and to express their own concerns.

3diii Encouraging supply of missing aspects of support

Respondents sought new sources of support when their needs were not being met within their existing social networks. Grouping of patients over three days of

diagnostic and staging procedures and later in the hospital, encouraged development of peer support groups. The nurse counsellor provided information to patients on local and national self help groups. However, few patients joined these groups since they already had peer support in the hospital. One husband described the support he had received from talking to a friend's wife who had had a mastectomy. This indicates a need for support groups for partners as well as patients. Nurses could play a role in setting up groups for patients and partners. They could also introduce patients to people who have recovered from breast cancer and who can act as role models.

4 Identity and support in a wider context

This research indicated that health visitors with preparation and education for the role, are in a unique position to provide effective support to patients having treatment for breast cancer within the community. Such support, involving medical, psychological and social skills, cannot easily be provided by informal carers who, in any case, may need support themselves. It cannot often be given by other professionals such as GPs who usually lack the time for much home visiting or even by specialist breast care nurses if they are hospital based and carrying a heavy work load. Health visitors were felt by myself and by community nursing management to be the appropriate community nurses to support patients with breast cancer. In the near future, the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (1991) envisages the creation of a new community nursing discipline encompassing district nurses, health visitors and other community based practitioners. In doing so, however, it acknowledges the range of specialisms already developing in community nursing practice and envisages future practitioners who will acquire specialist skills to meet needs identified within the community. Hopefully, nurse managers and community nurses of the future will recognise the needs for professional support in the community of patients with breast cancer and be encouraged to provide it by these research findings. We must have health visitors to give this kind of support in the future.

4a Social support and nursing education

Educators wishing to develop in nurses, skills in social support should focus initial education on increasing their awareness of the threats to identity which arise in various patient and client groups. In major illness, patients go through critical

phases in redefining their identities. Failure to cope means that some aspects of identity remain under threat and the crisis is unresolved. In these cases, patients may recover physically but not psychologically. Formal and informal support is needed to enable patients to pass through these critical phases and reach self acceptance. Nurses are involved in many situations where people need to develop a new sense of identity and in various roles providing support directly to patients or indirectly by enhancing the support available in their social networks.

Major illness (physical or psychiatric)

Disasters

Life cycle changes eg. childbirth, retirement, occupational changes

Bereavement

Health promotion and changes in health related behaviour

Situations of lack of support

4ai Building up identities

Respondents indicated that there were many opportunities for professional and informal carers to affirm or help them cope with changes in their identities. Professionals must further develop skills to build up their clients' identities. One tool in meeting this objective might be use of discourse analysis to note ways in which clients/patients positively or negatively marked their identities in statements relating to an illness or crisis.

The process of building identities starts with careful assessment of clients' self concepts, threatened aspects of identity and existing sources of support. Important questions are, How does the individual see him/herself? What is important to him/her? What are his/her significant relationships, future plans, important roles? What aspects of the person's identity are threatened in the present situation? What formal and informal support is available? Clients' network diagrams could assist in assessment of perceived support.

Planning care would involve use of appropriate formal and informal support. Respondents indicated that informal support was important to identity maintenance and change and therefore to their recovery. As having a variety of support types and sources was beneficial, professionals should seek to keep clients' networks as wide as possible. When some types of support are lacking,

professional carers can sometimes introduce or promote them. Experiential support provided through peer and self help groups is an example of this.

Professionals could use discourse analysis to evaluate effects of support in maintaining or changing aspects of identity noted in the assessment.

Nurses and other professionals should improve their skills in building up clients' identities. These include promoting their autonomy by involvement in planning and decision making, teaching them practical skills and promoting coping through expression of feelings, problem solving and role modelling. Frequent affirmation is very important in developing self confidence and self esteem.

In his 'Quality of Life An Assessment in Cancer Patients', Calman (1987) noted that the aim is to try to help people to reach the goals they have set for themselves. This definition of quality of life had four implications;

It can only be described by the individual

It must take into account many aspects of life

It must be related to individual aims and goals

Improvement is related to the ability to identify and achieve these goals

4a ii Undermining identities

Respondents indicated that some attitudes and behaviour from network members and professionals did not support their identities. Most negative behaviour resulted from a network member being unable to cope with the patients' breast cancer diagnosis due to a perceived threat to his or her own identity. Professional carers may also be unable to adequately support people in some situations and with some conditions for this reason. Respondents reported that overprotective behaviour towards them from network members negatively affected their self esteem and identity as independent people who were capable of giving as well as receiving support. Professional carers can also undermine clients' identities in this way when they encourage or allow the latter to become overdependent on them. Finally, my respondents felt stigmatised by their own negative perceptions of cancer and those of some of their network members. Initially, they saw themselves and felt that some saw them in terms of the label 'cancer victim'. This was their prime status, temporarily obscuring their other statuses as wives, mothers, workers. It is important that professional carers do not treat the individual's disease or situation

as his/her prime status but treat him/her as a person who happens to have a disease or handicap or be undergoing certain difficulties.

4aiii Identity and motivation for support

The pilot study and interviews in the first part of this research showed that, to provide effective support, it was important that health visitors liaising with the Breast Unit were motivated to care for patients with breast cancer and that they were given the education and support necessary to carry out this role. Professional carers should examine their own motives for feeling less attracted to supporting people with some conditions or in some situations than others. It may be that these conditions and situations threaten aspects of their personal or professional identities. For example, contact with patients with breast cancer may increase some nurses' perceived vulnerability to developing the disease. Being asked to care for such patients while lacking education about or preparation for this role is likely to threaten their identities as competent professionals.

4aiv Social identity and limits of support

Health visitors reported that supporting patients with breast cancer could be emotionally draining and that they needed support from colleagues and nurse managers. Some colleagues provided a listening ear, a willingness to discuss problems which arose with patients with breast cancer and a willingness to visit some of these patients themselves. Some nurse managers, through regular meetings with health visitors showed an interest in this new breast care role and ensured that health visitors had time for their own educational updating and that of their colleagues in the community. Occasional social meetings arranged by the researcher for the health visitors involved in breast cancer care were felt by those involved to provide much support.

4b Other situations of identity maintenance, or change

Since there are many situations in which people's identities need to be developed, maintained or changed the findings of this research will be of wider interest than to those concerned with the support of women with breast cancer. In crises of many kinds, peoples' identities are threatened and they need support from both formal and informal sources.

The main target group of helpers in this study was nurses. However, the findings of the study are relevant to other helpers in formal and informal situations. For example, social workers and clergy. Support groups help people in a variety of situations to come to terms with changed perceptions of society towards them and to change aspects of their identities.

5 Afterthoughts about Method

The ways in which methods were adapted for this thesis may be of interest to other researchers.

In order to fully utilise my 'old' data from a previous study for this thesis, I decided to adapt the grounded theory approach of Glaser and Strauss (1967) and to analyse this data retrospectively. The main Macmillan Study formed the core of data for analysis but data from the Pilot Study and Home Interviews was also used to 'saturate the categories' which were uncovered, that is to develop as far as possible, all the properties of the main theories. Glaser and Strauss (1967) indicated that single data sources could only yield a few categories and some of their properties. This implies that a category developed by studying only one data source cannot be considered saturated. For example, in the Main Study, there were five patients with recently diagnosed, inoperable but treatable tumours and only three with advanced disease. In order to more adequately compare and contrast perceptions of identity and support among these patients and among those those being treated for primary breast cancer, it was useful to be able to draw on data from the Pilot Study and the Home Interviews, where there were there were a further 10 patients with recurrence/advanced disease. In studying social support and identity maintenance and change, it was important to have a time perspective. I conducted a longer term follow-up of ten patients from the Main Study for this reason. Had time permitted, it would have been interesting to have followed more patients up for longer. However, I supplemented data from these ten patients by comparing and contrasting their responses with those of 10 patients participating in the Home Interviews who had been diagnosed one year to several years previously.

I found that discourse analysis was a useful approach to testing retrospectively, my hypothesis about the connection between social support and identity maintenance and change. Using this method, I could test out my insight about this connection by examining respondents' statements to see how they symbolised their identity and

how their network members symbolised their identity since diagnosis with breast cancer. Discourse analysis was an appropriate method to a study of the meaning of social support because it is concerned with the language that people use in interviews, committees and in everyday interactions to describe their perspectives. In study of language and social identity, Gumperz (1982) noted that

... social identity and ethnicity are in large part established and maintained through language. p. 7

As already discussed, six main aspects of identity were noted from respondents' statements. For example, many women spoke of losing a sense of permanence in their lives ('I don't seem to be able to get it [cancer] out of my mind') and being confronted with their own mortality. Discourse analysis also showed how identity was not a constant but communicatively produced. For example, the women spoke of being labelled sick ('suddenly someone tells you you've got cancer') or in some cases, labelling themselves as sick ('I knew before I went what it was').

Ego centred network analysis enabled me to gain more information about social support than would have been possible from the interviews alone. Patients' network diagrams illustrated the following;

- 1 the relationships between types and sources of support
- 2 the balance of support and strain in networks
- 3 changes to patients' network membership since their illness
- 4 network size
- 5 balance of formal and informal support in networks
- 6 the importance of different sources of support as indicated by where respondents placed network members within their diagrams in relation to themselves at the centre.

From health visitors' network diagrams I learned about their perceptions of their role and position in patients' social networks. I was able to compare and contrast patients and health visitors network diagrams.

I increased the reliability of my interviews with patients in the main Macmillan Study by asking them to draw network diagrams. These confirmed what they had said during the interviews or in some cases produced additional data not mentioned during the interviews. For example, network members not mentioned in the interviews were sometimes included in the diagrams.

6 Women's identity and support in society

Respondents described various threats to their identities posed by their breast cancer and by attitudes of society towards female sexuality and women's roles in the family. For example, they identified strongly with their family roles as partners, mothers, etc. The prospect of changes in these area threatened their identities and they wanted to resume their normal family roles as quickly as possible and to hide their own anxieties to protect family members from stress. This could mean neglect of their own health needs.

The attitudes of society towards female sexuality increased the threat of breast cancer. Delays in reporting signs of their breast cancer were largely due to fear of cancer but fear of losing a breast was also a factor. Attitudes and expectations of society towards women's physical appearance also played a part in the decisions of some women to have breast reconstruction.

This thesis indicates a need for more public education about female sexuality. It also demonstrates the role that health care professionals can play in educating and supporting the family members of patients with breast cancer so that they can cope with threats to their own identities and thus be better able to support the patient. Partners in particular can play such an important part in affirming women's sexual identity. The role of women in supporting each other should be recognised by health care professionals who should encourage peer support and support groups to provide experiential support.

Women with breast cancer can feel powerless due to the impact of their disease on their self confidence. This thesis showed that they do not always get the support they need from health care professionals and particularly from doctors because they do not always make their needs known. Nurses especially should seek to empower women by acting as their advocates, encouraging them to ask questions about their disease and treatment and giving them the information they need to make informed treatment choices when possible. Women who have had mastectomies should be encouraged to assert their rights to choose from a wide and not restricted range of breast prostheses since satisfaction with the latter is so important to boosting self confidence.

7 Indications for future research

This thesis gives indications for future research. Six identity crises reported by respondents and the support needed for their successful resolution invite further exploration among patients with breast cancer and other client groups. Research into social support and identity maintenance and change will be more emphatic if the longitudinal dimension is incorporated into the design. Longitudinal studies should explore whether changes in self concept and in patterns of support (eg. peer support, changes in family roles/attitudes) resulting from a crisis are permanent or temporary.

This thesis emphasised the key role of partners in affirming women's sexual identities after a diagnosis of breast cancer. There is need for further research to explore partner's feelings and difficulties in similar circumstances and to evaluate the roles of professionals and informal support such as partners' peer groups in supporting partners.

My data indicated that respondents' female relatives and children might feel threatened by the breast cancer diagnosis. Further research should be conducted to see if such reactions occur in similar situations, and how these relatives can best be supported.

The importance of support from peers shown in this thesis should be noted by professionals caring for patients with breast cancer and other conditions and by voluntary and charitable organisations like Breast Cancer Care. Sociological research and voluntary services should explore the effects of experiential support from various sources on maintaining and changing peoples' identities. Sources of experiential support could include contemporaneous peers, people who have been through the experience and who act as positive or negative role models, support groups.

This thesis indicated that recurrence was a time of great anxiety for respondents.. However, professional and informal support was often diminished at this time. Future research should explore what support these patients want and how best to create it.

Future professional research should explore the influence of women's identities on their attitudes to various aspects of their health from screening for disease

prevention, to coping with different illnesses/handicaps. This would provide indications of how to make formal and informal support in promoting women's health more effective. Nurses should explore ways of promoting a healthy identity in their patients especially those suffering from conditions like breast cancer who face an uncertain future. My respondents substituted their own indicators of recovery in absence of professional reassurance, for example, 'getting back to normal', 'going back to work', 'valuing my family more'. Nurses could help patients to find indicators of health within the illness experience.

Professional research should explore how to incorporate the concept of identity into quality of life indexes. Threats to identity from illness/disability could be assessed, self perceptions explored and formal and informal support needs evaluated.

A breast cancer diagnosis is a traumatic experience for any woman but appropriate professional and informal support can greatly alleviate it. AC describes her feelings.

Eighteen months after first discovering the lump, it has been conquered. ... I have nothing to worry about for the time being. I feel a different person completely now and it is just not possible to describe how light-hearted and free I feel. There has been much heartache and mental anguish but, with the help of my husband, family friends and colleagues, I have come through it - WE have come through it!

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Appendix 1

Abstract for the Macmillan Project

The first part of the Research Project took the form of a survey of patients with breast cancer who were having treatment in the community, in order to identify their concerns about the disease and its treatment, their sources of informal and professional support and the extent of the help they had received from a Hospital Breast Unit-community Liaison Health Visiting Service.

A Pilot Study and interviews with a further group of patients both indicated that the Breast Unit Liaison Health Visiting Service was not reaching the majority of women included in the survey. Of 29 patients who participated in the Pilot Study, only seven had received a visit at the time of contact. Later interviews with a further 18 patients revealed that only four had been visited by the Health Visitors. In the few cases where a Health Visitor had made contact, most of these patients commented that their visits had been helpful. Health Visitors for the patients referred but not visited were contacted. Three of these said that their priorities lay with children and families under stress and three expressed the view that they did not have enough expertise in breast cancer nursing.

The original plan for a fairly large and controlled study of Health Visitors' support of patients with breast cancer was considered to be inappropriate in the light of results of the Pilot Study and later Interviews. It was decided to conduct a smaller, descriptive study. It was considered that if Health Visitors were invited to participate in the Research because they had expressed an interest in working with patients with breast cancer, they would be highly motivated to give good support to patients.

The aims of the revised Research Project were as follows;

- 1 To explore the needs for help and support in the community of patients having treatment for breast cancer.
- 2 To examine in particular the possibility of optimising professional support by focusing on what support Health Visitors can and should provide at various stages in the lifetime of breast cancer and its treatment.

- 3 To make recommendations for the training and support of Health Visitors in caring for patients with breast cancer, leading to successful co-operation between hospital and community based staff.

Method

Seven Health Visitors from the City of Edinburgh and from Midlothian agreed to participate in the Study. At the outset of the Project, the Health Visitors completed a questionnaire which showed that all except one Health Visitor with previous experience in breast cancer care, perceived their knowledge, skills and confidence in this area to be limited. After a brief education programme and experience with between 4-6 patients, Health visitors again completed the same questionnaire which showed that their perceived their knowledge and skills and confidence had increased in all aspects of caring for these patients. The researcher conducted semi structured, tape recorded interviews with each Health Visitor 2-3 months into the research period and 8 months later. The aim of the interviews was to find out how they were coping with additional patients in their caseloads, their attitudes towards their new role, and their levels of confidence in their knowledge and skills in caring for patients with breast cancer. They were also asked to identify the key problems they encountered among the patients they were visiting and the type of support they had given or planned to give in each case. The problems identified by the Health Visitors were compared with those identified by the researcher in her interviews with the patients and the extent of agreement between the 2 sets of observations was examined. The Health Visitors were asked to complete a Domiciliary Assessment Form for each patient. The Domiciliary Assessment Forms were used to record patients' physical and psychological states and any changes over the time period of the Health Visitors' visits.

A sample of 35 patients, consisting of 32 women having a variety of treatments for primary breast cancer and 3 women with recurrence was recruited during an 8 month period. The Researcher conducted 2 semi-structured, tape recorded interviews with each patient at her home. Patients were interviewed soon after their referral from hospital and again 2-3 months later when Health Visitors would have had time to visit. Patients were asked whether they had any problems, how they were coping and what professional and informal support they were receiving. At her second interview with each patient, the Researcher asked the latter to draw a diagram of her main informal (family, friends etc.) and formal (professional) social

contacts and to describe the helpful or unhelpful behaviours shown by each person in the diagram since her cancer diagnosis. The Health Visitor's position within the diagram was noted as were the patient's perceptions of her role and support.

Results

Patients with breast cancer having treatment in the community, had many problems and anxieties in relation to their disease and its treatment, thus indicating need for professional support.

Patients medical problems were usually related to their treatments, but in the cases of patients with advanced breast cancer, also to their disease. Problems due to treatment extended over several months.

The main psychological problem identified was anxiety about the cancer diagnosis and its possible implications for the future. Some patients were also concerned about the effects of surgery on their body image and sexuality, while a third of the patients had had periods of depression. Patients' anxiety and uncertainty about the future tended to become less salient as their treatment was concluded.

Many social problems related to family relationships, finance, work etc. were identified. Patients' and Health Visitors' comments indicated that most of the husbands of married women were anxious about their wives' illness. The school age children of 5 patients showed overt signs of distress at their mothers' illness. Eight patients had long-standing difficulties in relationships with family members but 4 patients had experienced difficulties in their relationships with family members since their diagnosis with breast cancer. Ten patients (29%) had financial problems.

There was close agreement between the Health Visitors' and the Researcher's identification of patients' problems as they were described by patients. Health Visitors' reported that their awareness of potential medical psychological and social problems was increased by their educational preparation in breast cancer care, their receipt of adequate information about patients on referral from the Breast Unit through the Liaison Health Visitor and the Discharge Forms and their use of the Domiciliary Assessment Forms which provided assessment guidelines.

Most medical problems improved with time and Health Visitors assisted this improvement by preparing patients for treatments, giving information about treatments, giving advice, assessing patients' coping and liaising with General Practitioners and Breast Unit staff over some medical problems.

Psychological problems also improved or were less salient in patients' minds as their treatment progressed. Many patients mentioned the availability of the Health Visitor to come and see them as being important in allaying their anxieties. Also important were her ability to listen and allow them to express their feelings. Nine patients mentioned the usefulness of the Health Visitors as professional people who were more detached from their situations than were family and friends and to whom they could express their deeper anxieties.

Half of the patients' social problems were completely alleviated or improved. Patients were helped considerably with financial and practical problems by the Health Visitors. Patients also appreciated being able to discuss family relationship problems and children's adverse reactions to their illness with Health Visitors.

In 13 cases (37%) patients' comments indicated that Health Visitors' support was very important to their coping with their illness and its treatment. The women in this group had severe problems/anxieties.

In 17 cases (49%), patients' comments indicated that the Health Visitors' support had been important to their coping with their illness and its treatment. Health Visitors had visited patients in this group less frequently than those in the first group but in many cases had supported them through a particular crisis.

In 4 cases (11%), patients' comments indicated that although they were pleased to receive a visit, Health Visitors' support had not been very important to their coping with their illness and treatment. One of these patients had received several visits from district nurses. In another case, there was a delay before the Health Visitor was able to visit. All 4 patients had only received one visit.

One patient who had initially wanted a Health Visitor to call later became very upset for other reasons and did not want help. However, she discussed with the health Visitor the possibility of receiving financial help.

The findings of this Research Project indicate that patients undergoing treatment for breast cancer in the community have problems and anxieties for which they require professional support. Health Visitors with an interest in breast cancer care and with education and preparation for the role, are in a unique position to provide such support.

Appendix 2

The Health Visitors' Education Programme

The Preparation and Education of the Health Visitors

A programme of education was planned to increase the Health Visitors' ability to help patients with breast cancer in the community. As the period of study leave for the Health Visitors was limited, the aims of the initial education programme were modest. However, the Health Visitors also had the opportunity to attend a Study Day, organised by the Researcher, on breast cancer care, later in the research period. At the outset of the Study, the Health Visitors were each given a pack containing literature on medical and psychosocial aspects of breast cancer care and on staging procedures and the work of the various clinics within the Breast Unit. This information was augmented by the Researcher with other relevant material during the research period. The Health Visitors also contacted the Breast Unit Nurse Counsellor, the Liaison Health Visitor, and the Researcher on occasions when they needed information on aspects of breast cancer care.

Initial Aims of the Education Programme for Health Visitors

These were as follows;

- 1 Demonstrate an awareness of the diagnostic and staging procedures for breast cancer within the Breast Unit.
- 2 Display an awareness of the treatment protocols of the Breast Unit. (This would include treatments for primary breast cancer offered under the Scottish Primary Breast Cancer Trials, treatments to patients ineligible or unwilling to enter the trials and treatments offered to patients with advanced disease.)
- 3 Help the patient to cope with the knowledge that she has cancer and to the uncertainty of whether it will return after treatment.
- 4 Demonstrate an awareness of possible adverse effects of treatments for breast cancer (surgery, radiotherapy, chemotherapy, hormone therapy) and some ways in which patients may be helped to cope with them.

- 5 Demonstrate sensitivity to psychological problems which may be experienced by patients with breast cancer.
- 6 Recognise the needs of patients' relatives for support.
7. Demonstrate awareness of help for patients, available from volunteers and self-help groups.

The initial education programme consisted of a half day Introductory Session, a (half) Study Day, attendance at clinics, a visit to the Radiotherapy Department, and optional sessions in areas of the Health Visitors' own choice.

The Introductory Session

There was an opportunity for the Health Visitors to meet for the first time as a group, to see the facilities available within the Breast Unit and to meet the staff of the Breast Unit and the Liaison Health Visitor. The Research Protocol was discussed by the Researcher with the Health Visitors and the liaison procedures explained. Use by the Health Visitors of the Domiciliary Assessment forms was also discussed and these were given to the Health Visitors together with the guidelines for their completion. The Health Visitors were each given a folder containing literature and booklets on all aspects of breast cancer care.

Study Half Day

This was an opportunity for the Health Visitors to hear from the staff about the care of patients within the Breast Unit. The topics and speakers were as follows;

The Ward Sister	The nursing care of patients with breast cancer within the Breast Unit.
The Nurse Counsellor	The needs of patients with breast cancer for information and support.
Consultant Surgeon	Treatments for patients with breast cancer under the Scottish Primary Breast Cancer Trials and outwith the Trials.

Clinic Sessions

The clinic sessions provided valuable opportunities for the Health Visitors to talk to the patients and learn about their reactions to having breast cancer and their feelings about the treatments.

The Health Visitors attended the Staging Clinics. Here the results of Staging of each patient's breast cancer and the treatment options are discussed first among the medical and nursing staff and then with the patient and her relatives.

The Health Visitors also attended the Combined Breast Clinics so called because the patients who attend have recurrence of the disease, or inoperable or advanced breast cancer and a variety of treatment options or a combination of treatments is being considered by radiologists, oncologists and surgeons.

Health Visitors attended chemotherapy sessions to observe patients having adjuvant chemotherapy, and palliative chemotherapy. There was also an opportunity to observe some patients having scalp cooling to prevent chemotherapy induced hair loss.

The Radiotherapy Department

The Health Visitors attended the Radiotherapy Department to learn about the use of radiotherapy in breast cancer and care of patients having radiotherapy. A large number of patients from the Breast Unit receive radiotherapy as adjuvant treatment and some as palliative treatment.

Optional Experiences

The Health Visitors also had the opportunity to learn more about other aspects of breast cancer care, and some chose to attend the Tissue Expansion Clinic where tissue expanders are inflated over several weeks prior to insertion of breast implants. Others attended the Prosthesis Fitting Clinic and the Stereotactic Fine Needle Aspiration Clinic.

Appendix 3

**Longmore Hospital (Breast Unit) Nursing Research Unit
Cancer Relief Macmillan Fund Project**

**Home-Hospital Liaison : An Exploration of the Effectiveness of Health Visitors'
Support of Patients with Breast Cancer**

**Health Visitors' Objectives and Perceived levels of Competence and Plan of
Action**

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March 1991**

General Learning Objectives for Health Visitors Supporting Patients from the Breast Unit

1. Demonstrate knowledge of the aetiology and clinical features of breast cancer.
2. Demonstrate knowledge of diagnostic and staging procedures for breast cancer within the Breast Unit.
3. Display knowledge of the treatment protocols of the Breast Unit. (this would include treatments for primary breast cancer offered under the Scottish Primary Breast Cancer Trials, treatments for patients ineligible or unwilling to enter trials).
4. Be able to identify psychological problems which may occur in patients who have/had breast cancer and know how to support such patients or when to refer them for further medical help.
5. Demonstrate knowledge of the medical and nursing care of patients with metastases from breast cancer.
6. Be able to identify possible needs of relatives of patients with breast cancer for information and support and know how to provide such support.
7. Demonstrate knowledge of the help available for patients with breast cancer from volunteers and self-help groups.

Please study the learning objectives and indicate in the following pages your perceived levels of competence for each objective. There is space on pages 11-13 for you to add objectives which have not been included, but which you consider to be important and your desired plan of action for future learning.

Knowledge
(specimen of Questionnaire)

- (A) Your existing level of knowledge in particular area?
 Enter 0-5 in column. 0 = no knowledge, 5 = expert.
- (B) How important do you think this item of knowledge will be in your clinical practice?
 Enter 0-5 in column. 0 = no importance, 5 = very important
- (C) How do you feel about this area of knowledge?
 Enter 0-5 in column. 0 = not at all important, 5 = very important

Area of knowledge	Perceived level of knowledge 012345	Perceived importance to practice 012345	Perceived level of interest 012345
Objective 1			
Demonstrate knowledge of the aetiology and clinical features of breast cancer.			
(A) Know the risk factors for developing breast cancer	3	5	5
(B) Know the incidence of benign and malignant breast disease	2	5	5
(C) Know the clinical features of localised and systemic breast disease	3	5	5
Objective 2			
Demonstrate knowledge of diagnostic and staging procedures for breast cancer within the Breast Unit.			
(A) Discuss screening and diagnostic tools in current use for breast cancer	1	5	5
(B) Discuss classification and staging of breast tumours	0	5	5
(C) Discuss investigative procedures for staging of breast cancer	0	5	5

Area of knowledge	Perceived level of knowledge 012345	Perceived importance to practice 012345	Perceived level of interest 012345
Objective 3			
Display knowledge of the treatment protocols of the Breast Unit (including treatments for primary breast cancer offered under the Scottish Primary Breast Cancer Trials and treatments for patients ineligible or unwilling to enter the trials.			
(A) Discuss protocols for small tumours	1	5	5
(B) Discuss protocols for large tumours	1	5	5
(C) Discuss protocols for elderly patients	1	5	5
(D) Discuss treatment for fungating tumours	1	5	5
(E) Discuss types of reconstructive surgery	2	5	5
(F) Describe adjuvant chemotherapy for breast cancer	1	5	5
(G) Describe adjuvant radiotherapy for breast cancer	0	5	5
(H) Describe adjuvant hormone therapies for a breast cancer	0	5	5
Objective 4			
Be able to identify psychological problems which may occur in patients who have had breast cancer and know how to support such patients or when to refer them for further medical help.			
(A) Recognise common stressors related to breast cancer and its treatment	4	5	5
(B) Discuss the type and incidence of psychological problems in patients with breast cancer	4	5	5
(C) Discuss the possible effects of breast cancer on an individual's body image and sexuality	4	5	5
(D) Know the symptoms of clinical anxiety and depression	4	5	5
(E) Discuss commonly used coping strategies during illness	4	5	5

Area of knowledge	Perceived level of knowledge 012345	Perceived importance to practice 012345	Perceived level of interest 012345
Objective 5			
Demonstrate knowledge of the medical and nursing care of patients with metastases from breast cancer.			
(A) Describe the patterns of metastatic spread in breast cancer and associated symptoms	2	5	5
(B) discuss the use of palliative surgery, chemotherapy, radiotherapy and hormone therapy in metastatic breast cancer	2	5	5
(C) Discuss the medical and nursing management of pain and other symptoms in metastatic breast cancer	2	5	5
(D) Discuss an individual's possible reaction and stages of adaption to recurrences of breast cancer	3	5	5
Objective 6			
Be able to identify possible needs of relatives of patients with breast cancer for information and support and know how to provide such support.			
(A) Discuss the possible effects of breast cancer on relationships between a woman and her significant others	3	5	5
(B) Discuss the information needs of patients' relatives at various stages of breast cancer and its treatment	3	5	5
(C) Discuss the support needs of patients' relatives at various stages of breast cancer and its treatment	3	5	5

Area of knowledge	Perceived level of knowledge 012345	Perceived importance to practice 012345	Perceived level of interest 012345
Objective 7			
Demonstrate knowledge of the help available for patients with breast cancer from volunteers and self-help groups.			
(A) Know the national and local voluntary organisations and support groups for patients with breast cancer	3	5	5
(B) Discuss the types of help offered by the national and local voluntary organisations and support groups for patients with breast cancer	2	5	5

Skill

- (A) Your existing level of skill in particular areas?
Enter 0-5 in column according to how you rate yourself 0 = no skill, 5 = expert.
- (B) The perceived importance of the skill to your clinical practice?
Enter 0-5 in column. 0 = no importance, 5 = very important
- (C) Your confidence in practising this skill?
Enter 0-5 in column. 0 = no confidence, 5 = very confident

Area of skill	Perceived level of skill 012345	Perceived importance to practice 012345	Perceived level of confidence 012345
Objective 1			
Demonstrate knowledge of the aetiology and clinical features of breast cancer.			
(A) Note normal and abnormal variations in breast appearances	4	5	5
(B) Note normal and abnormal variations associated with appearances of the nipple	4	5	5
(C) Demonstrate breast self-examination to patients (being aware of limitations of the procedure for detecting breast cancer)	4	5	5
Objective 2			
Demonstrate knowledge of diagnostic and staging procedures for breast cancer within the Breast Unit.			
(A) Participate knowledgeably in the physical, psychological and social assessment of women recently diagnosed with breast cancer	2	4	2
(B) Give information and support to enable patients to give informed consent to treatment	3	4	3

Area of skill	Perceived level of skill 012345	Perceived importance to practice 012345	Perceived level of confidence 012345
Objective 3			
Display knowledge of the treatment protocols of the Breast Unit (including treatments for primary breast cancer offered under the Scottish Primary Breast Cancer Trials).			
(A) Care for surgical wounds	4	5	4
(B) Obtaining and fitting external prosthesis	3	5	3
(C) Care of tissue expanders/internal prostheses	0	5	0
(D) Demonstrate exercises to regain range of arm movements after surgery	2	5	2
(E) Help prevent (when possible) and treat lymphoedema following surgery for breast cancer	0	5	0
(F) Care of patients having chemotherapy	1	5	1
(G) Care of patients having radiotherapy	2	5	2
(H) Care of patients having hormone therapy	0	5	0
Objective 4			
Be able to identify psychological problems which may occur in patients who have/had breast cancer and know how to support such patients and when to refer them for further medical help.			
(A) Assess individual's stressors, resources and coping	4	5	4
(B) Help patients to develop alternative coping strategies when necessary	4	5	4
(C) Help patients to use stress reducing coping strategies, such as relaxation	3	5	3
(D) Support patients with psychological problems	3	4	3
(E) Identify and refer patients with psychological problems in need of further medical help	4	5	4

Area of skill	Perceived level of skill 012345	Perceived importance to practice 012345	Perceived level of confidence 012345
Objective 5			
Demonstrate knowledge of the medical and nursing care of patients with metastases from breast cancer.			
(A) Participate in the care of patients with fungating wounds	0	4	0
(B) Participate in symptom management of patients with metastases	4	4	4
(C) Participate in the psychological support of patients with metastases	4	5	4
Objective 6			
Be able to identify possible needs of relatives of patients with breast cancer for information and support and know how to provide such support.			
(A) Facilitate communication between the patient with breast cancer and her significant others	4	5	4
(B) Identify and meet the informational needs of relatives of patients with breast cancer at various stages of the disease and its treatment	3	5	3
(C) Identify and meet the support needs of relatives of patients with breast cancer at various stages of the disease and its treatment	4	5	4
Objective 7			
Demonstrate knowledge of the help available for patients with breast cancer from volunteers and self-help groups.			
(A) discuss with patients the help available from national and local voluntary and self-help groups for people with breast cancer	3	4	4
(B) Establish personal contacts with national and local voluntary and self-help groups for people with breast cancer	5	5	5

Learning Objectives: Please identify areas of knowledge and skills you wish to focus upon. Add you own areas if desired.

	Date	Desired plan of action
<p>1. Demonstrate knowledge of the aetiology and clinical features of breast cancer</p> <p>(A) <i>I need to brush up on this</i></p> <p>(B)</p> <p>(C)</p> <p>(D)</p>	30.4.91	Reading
<p>2. Demonstrate knowledge of diagnostic and staging procedures for breast cancer within the Breast Unit.</p> <p>(A) <i>I am aware of the screening programmes but I hope to build a clearer picture.</i></p> <p>(B) <i>I would feel very hesitant discussing staging procedures with clients.</i></p> <p>(C) <i>Investigative procedures are not clear. Staging is a word not fully understood.</i></p> <p>(D)</p>		<p>Reading</p> <p>observation in the Breast Unit</p> <p>attend staging clinic.</p> <p>observation in the Breast Unit.</p>
<p>3. Display knowledge of the treatment protocols of the Breast Unit</p> <p>(A) <i>I have lots to learn here.</i></p> <p>(B)</p> <p>(C)</p> <p>(D)</p>		<p>visit to Radiotherapy Unit.</p> <p>observation of administration of chemotherapy.</p> <p>Reading about treatment protocols.</p> <p>observation of surgery carried out.</p>

	Date	Desired plan of action
<p>4. Be able to identify psychological problems which may occur in patients who have/had breast cancer and know how to support such patients and when to refer them for further medical help.</p> <p>(A) <i>I would be able to cope with this side of things fairly well.</i></p> <p>(B)</p> <p>(C)</p> <p>(D)</p>	30.4.91	<p>Discussion with psychologist</p> <p>Reading</p>
<p>5. Demonstrate knowledge of the medical and nursing care of patients with metastases from breast cancer.</p> <p>(A) <i>I am ready to learn more about this aspect.</i></p> <p>(B)</p> <p>(C)</p> <p>(D)</p>		<p>Reading.</p> <p>observation at Radiotherapy Department.</p> <p>Contact with St. Columba's Hospice or Fairmile Marie Curie Home.</p>
<p>6. Be able to identify possible needs of relatives of patients with breast cancer for information and support and know how to provide such support.</p> <p>(A) <i>I would like to know more about this.</i></p> <p>(B)</p> <p>(C)</p> <p>(D)</p>		<p>Talk to relatives of patients in the Breast Unit.</p>

	Date	Desired plan of action
7. Demonstrate knowledge of the help available for patients with breast cancer from volunteers and self-help groups.	30.4.91	
(A) <i>I need to brush up on this.</i>		<i>Contact self help groups & volunteers.</i>
(B)		
(C)		
(D)		

Appendix 4

Longmore Hospital (Breast Unit) Nursing Research Unit

Cancer relief Macmillan Fund Project

Specimen Discharge Summary

(Names and Addresses have been changed and
some details altered to protect confidentiality.)

Section 1: General Observations (all patients)

Date of discharge

2. 7. 91

Marital status

widow

Patient's name

Rosemary Sanderson

Age

55

Occupation

former cleaner - unable to work
due to poor health

Patient's address

10, Kirk St,
Edinburgh

Telephone Number

GPs Name and Address

Dr Richards,
Medical Centre
20, Grant place, Edinburgh

Telephone Number

Patient's religion and if important to her

practising Roman Catholic

Section 2: Physical Adjustment to Breast Disease (all patients)

Tumour size

4.3cm x 3.8cm

Right side
1 year history

Node involvement

N1.

Metastases

N1.

Patient's current understanding of breast disease

Still coming to terms with knowledge that she has breast cancer.

Treatment

Surgery

Right wide local excision + axillary node clearance 14.5.91

Chemotherapy

Radiotherapy

Radiotherapy to breast area only.

Hormone therapy

Tamoxifen 20mgs daily

Other

Concurrent illness

Hypertension

Current medication and dosage

Daily Atenolol 50mgs for hypertension

Diazepam for anxiety, 5mgs x 4 daily

Family history of breast disease

Maternal aunt had breast cancer - still alive.
Had mastectomy 10 years ago

Patient's experience of other malignancy

None.

For patients who have had surgery

Any pain	Site	Type	Severity
1. Tenderness	1. wound area + under arm	1. Tender skin around wound	1. Moderately severe when touched.
2. pain	2. in axilla.	2. on arm movement	2. moderately severe on movement.

Swelling

Slight, around wound area.

Arm mobility

Not very good yet.

Condition of wound

Discharge from hospital delayed because wound was draining++.

Prosthesis: tissue expander/softee (if appropriate)

N/I.

General physical condition on discharge (all patients)

Has hypertension + is overweight. Smokes+++ very anxious.
General physical condition, fair

Section 3: Key Relationships (all patients)

Husband or partner

Widow.

Significant others (specify)

lives with 2 daughters. Son living away from home has drink problem.
parents in poor health

Section 4: Social Adjustment (all patients)

Any problems with:

Housing

No problems

Work

Has been unfit to work for 8 months.

Financial state

financial problems Gets widow's pension (£44) + income support (£11.30)
Son + daughter often asking for financial help.

Section 5: Psychological Adjustment

General reaction to breast cancer

Too scared to attend for screening in 1989. Presented with nearly a years history of lump in right breast.

How coping

Needing to talk about her problems. Very anxious at present & frequently tearful.

Anxiety

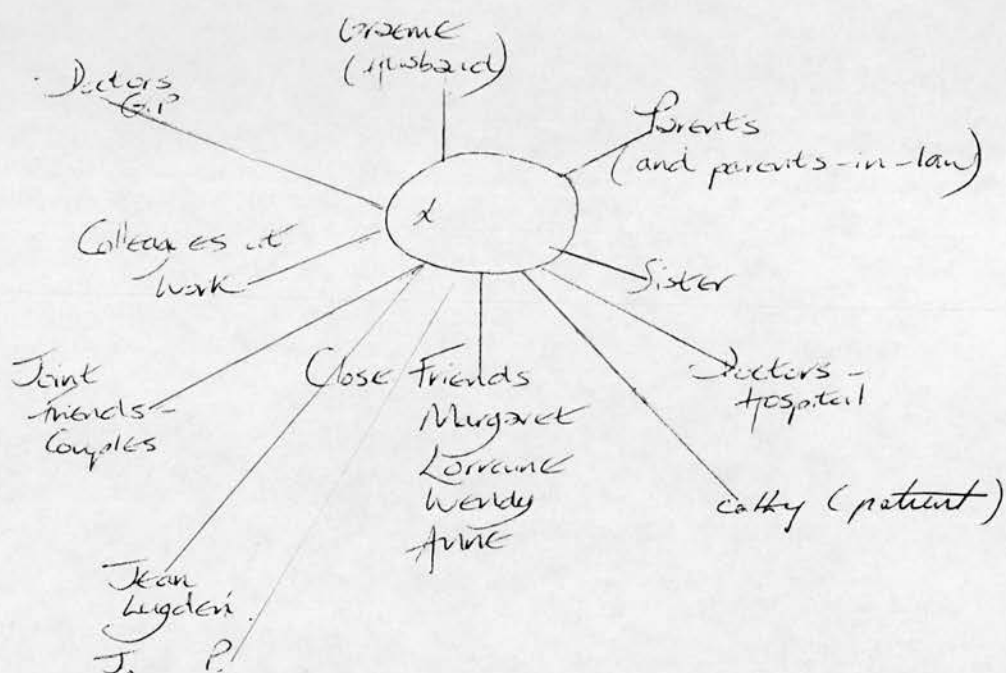
Very anxious with family & social problems.

Depression

Very tearful. Says she feels depressed & lacking in energy.

Appendix 5

L. B. (patient's diagram)



GP
Hospital more knowledgeable
re. treatment. Gets info. from
hospital.

Hospital doctors
Supportive + helpful - relaxed
approach.

work colleagues + bosses

Kept in touch. Have been
out for meals etc.

close friends

Talking about coping
Cathy (patient)

in hospital together but only
1 night met again at hospital
knows L's mother in law.

Husband
main support (emotional),
practical support - comes to
clinics etc.

parents
sees a lot
parents in law

sees a lot. on holiday
with them.

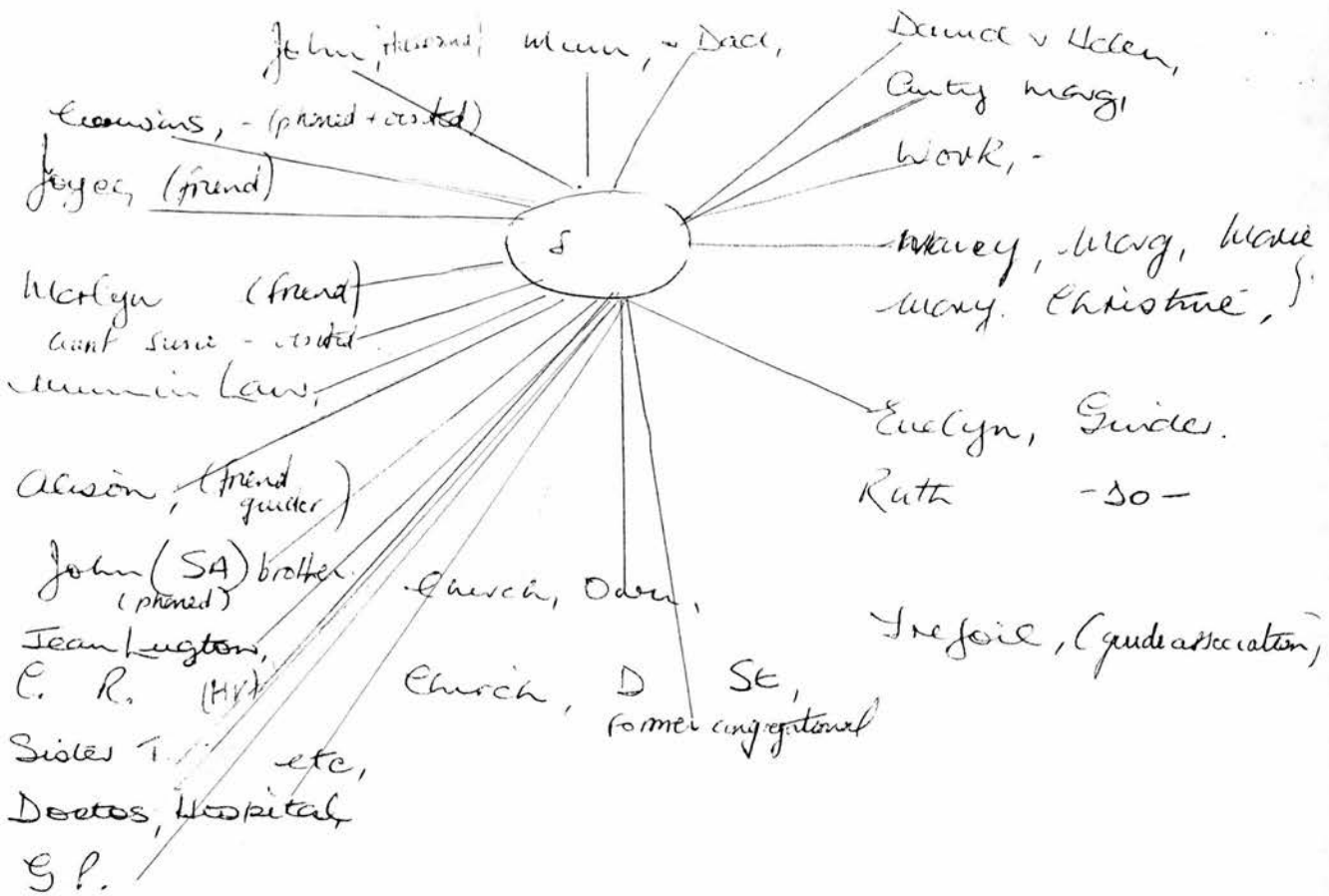
Sister

Helpful.

HV

Someone outside, available
if needed. Discussed
treatment + everyday things.
works in L's old practice.
Support group
Doesn't want to meet older
women. Want to talk to young
woman who has had treatment

S. S. (patient's diagram)



David & Helen

Brother & sister in law

work

with colleagues & boss supportive

Nancy, Mary, Marie

friends, have been supportive. visited her in hospital.

Trefoil

guide association. long standing connection with guide movement

John

Husband, provided emotional support.

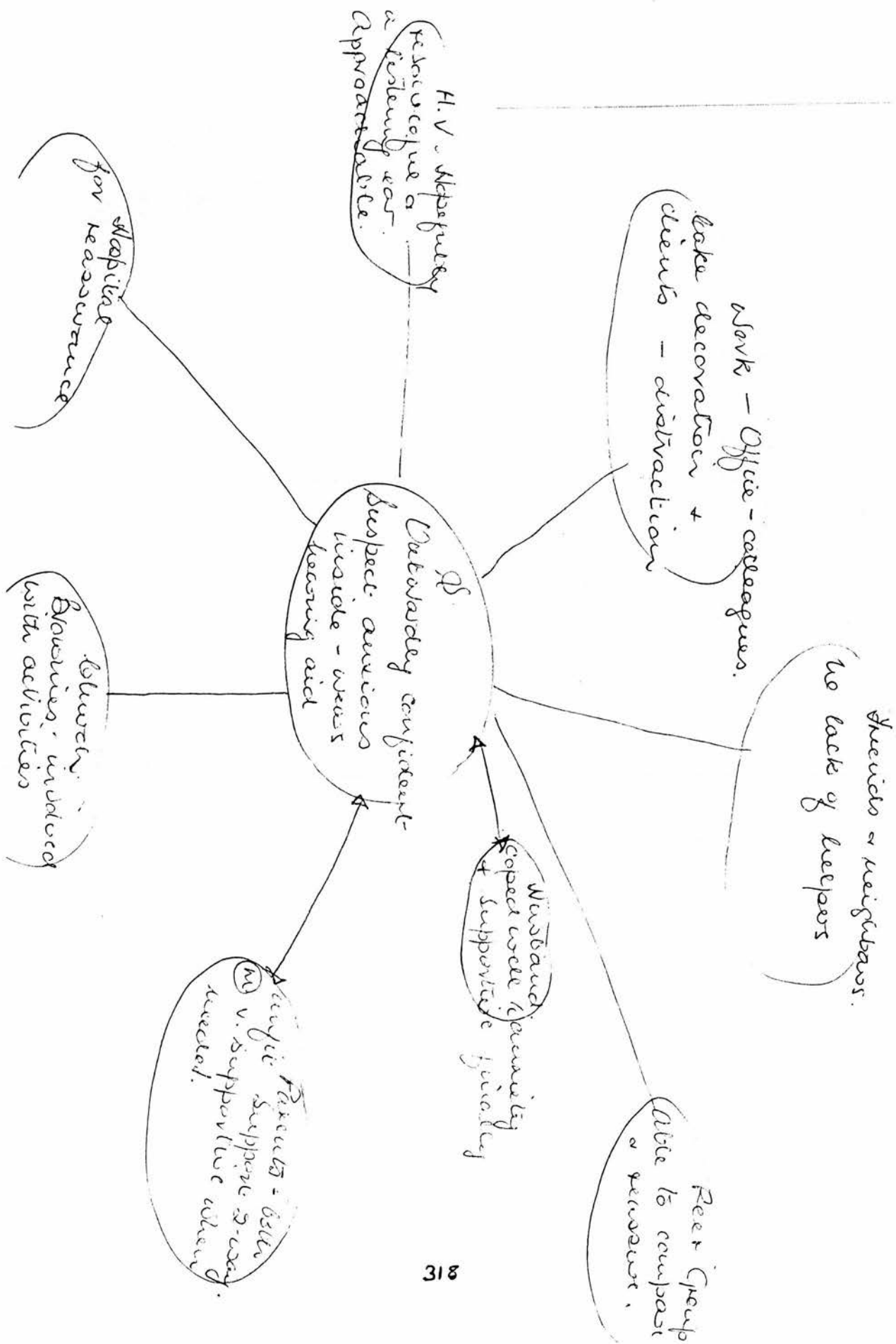
church

nuns & priest supportive.

Health visitor

available if needed. good to have someone to talk to.

C.R. (health visitor's diagram for S.S.)



Appendix 6

Longmore Hospital Breast Unit Sample Domiciliary Assessment Form

(Names and Addresses have been changed to protect confidentiality.)

Section 1: General Observations (all patients)

Date of discharge

2.7.91

Marital status

Married

Patient's name

Rachael Robertson

Age

35

Name patient likes to be called

Rachael

Occupation

partner in family shop

Hours worked

full time

Address

98, Green Drive
Edinburgh

Telephone Number

GP

Dr Brown
Medical Centre
10, Alt St, Edinburgh

Telephone Number

Patient's religion and if important to her

Church of Scotland. Not
a church attender

Patient's appearance

attractive, well groomed.

Who else present

nobody

Home (general description)

well kept, bright, smart

Section 2: Physical Adjustment to Breast Disease (all patients)

Tumour size	Node involvement	Metastases
4.8 x 4.6 cm	yes	no

Patient's current understanding of breast disease

appears to have knowledge & understanding.

Treatment	Surgery	Chemotherapy	Radiotherapy	Hormone therapy	Other
	1t Mx2 LD flap A.N.C.	5 treatments CMF.			

Concurrent illness

None

Current medication and dosage

None

Previous experience of breast disease

None

Previous experience of other malignancy

None

Questions for patients who have had surgery

Any pain	Site	Type	Severity
Moderate	shoulder	on arm movement	

Swelling

None

Arm mobility

Fair - improving

If doing exercises

Yes

Scar - looked at it reaction

accepted it well. It was as she expected it to be but she is aware that if the diagnosis was made earlier, a lumpectomy only might have been necessary.

Prosthesis

Has had mastectomy with latissimus dorsi flap reconstruction. Internal prosthesis inserted.

Bra

No. wears camisole

Patient's view of figure

Does feel that the internal prosthesis is rather high. Hopes it will drop in time. She is reluctant to wear revealing clothes at present for this reason.

Patient's view on clothing

Clothes are important. She likes to dress fashionably.

Section 3: Key Relationships (all patients)

Husband or partner

Being supportive -

practical

Has helped initially with household chores & also relieved her of her duties at the shop.

emotional

They have shared her anger & fears for the future. He has reassured her of his love.

sexual

Have resumed sex life but a little more exploration at the next visit will be appropriate.

Family - who (specify)

Being supportive -

practical

mother, mother in law, sister, brother, son David (14)
Daughter Fiona (12)

mother helps with chores. children doing small tasks

emotional

discussed her feelings about the cancer with mother. Told her of her shock & anger. Explained about her cancer to the children who seem to be coping well.

Friends - who (specify) *1 close girl friend*

Being supportive - practical

yes.

emotional

yes. Talking about her shock at being told after so many months that her suspicions were right.

Support group/counsellor (specify)

Being supportive - practical

emotional

interested in going to the local group when treatment is finished

Peer group (fellow patients)

Has made friends with 2 other patients

Being supportive - practical

emotional

can phone them + discuss her feelings about breast cancer, the treatments etc

Section 4. Interaction with Health Care Team since leaving Hospital

Hospital clinic doctor *Has clinic appointment to attend in 2 months.*

Hospital nurse *No*

Social workers *No*

General practitioner *Not since discharge.*

District nurse *Yes, on 2 occasions for dressings to scar.*

Health Visitor *She had a slight discharge from wound.*
Yes

Macmillan nurse *No*

Other

Supportive relationships with Health Care Team (specify)

practical *District nurse*

emotional *Health visitor, hopefully*

Section 5: Social Adjustment (all patients)

Any problems with the following:

Housing

No

Chores

No. Has help from her mother & offers of help from friends.

Work

No. Own business so can be flexible. Husband has control at the moment.

Financial state

No

Extent of leisure activities

None. Her family, home, the job are her main interests

Section 6: Psychological Adjustment

General reaction to breast cancer

Has accepted her condition but is upset about the delay in diagnosis. Had lump for several months but afraid to report it.

Any stressful events since hospital discharge/or chronic difficulties

No

Any sleep change

No

Any weight change

Has gained several pounds but looks quite attractive

Any appetite change

Yes. Eats more when at home & also when stressed.

How coping

Is aware of her weight gain & will work on controlling her eating habits. Coping well but worried about future

Overall anxiety

(comment on tension, irritability, panic feelings, lack of energy, impaired concentration, sleep disturbance)

Ring degree of anxiety

Mild

Moderate

Severe

worried about the future. anxious about the effects of delay in diagnosis. also worried about her body image. not very happy with the position of her internal prosthesis.

Overall depression

Lack of energy, impaired concentration, loss of interest, guilty feelings, hopelessness, sleep disturbance)

Ring degree of depression

None

Mild

Moderate

Severe

still shocked at diagnosis

Confided true feelings to anyone. Who?

mother, husband, girlfriend

Section 7

Key problems

Action taken or pending

1) worries over delay in diagnosis

1) Discussed her feelings & worries about the future. put her in touch with local support group.

2) worried about her appearance. feels that her internal prosthesis is too high.

2) advised to wait & see if prosthesis would drop with time. If still worried, to discuss with Surgeon at next clinic appt. Discussed her feelings about her body image.

3) Discussed administration of chemotherapy, possible side effects. Has wig in case of hair loss.

Guidelines to Completion of Assessment Form

Notes on the use of Domiciliary Assessment Form

Aims: To monitor the physical, social and psychological state of the patient. The main area of enquiry are:

Section 1. General Observation

Section 2. Physical Adjustment to Breast Disease

Section 3 Key relationships with significant others, such as partner, family and friends

Section 4. Interaction with Health Team

Section 5. The Patient's Social Background

Section 6. The Patient's Psychological State

During the interview, the patient may voluntarily raise points. The health visitor will want to pick up cues as and when they arise and therefore be flexible about the order in which she goes through her checklist. Many patients like to start the interview by talking about their operation and breast disease. The assessment form should be filled in **after** the interview so as not to impede fluency.

Section 1. General Observations

These include identification of existing or potential problems in the home, lack of personal grooming, clothes that may conceal rather than reveal the figure, or the patient not wearing a prosthesis.

Section 2. Physical Adjustment to Breast Disease

Breast disease staging to be recorded from discharge form.

Patients' current understanding of breast disease. Find out what patient has been told about her breast disease and what she understands about it.

Treatment (surgery, chemotherapy, hormone therapy, radiotherapy, other). Specify side effects. Question examples: How long do these symptoms last? Have they stopped you doing things? What sort of things?

Other concurrent illness: Have you any other medical problems apart from your breast disease?

Other current medication: Specify drugs, dosages and times taken and if any side effects.

Previous experience of breast disease: has anyone else in the family had breast problems? How do you feel about that?

Previous experience of other malignancy. Has anyone in the family had cancer? How do you feel about that?

Physical adjustment to breast disease. Questions for patients who have had surgery:

Swelling: Specify which are and area of it is affected. Also the duration and frequency of swelling. Measure and record the normal and affected arm at wrist, 5" below elbow, 5" above elbow and axilla.

Arm mobility: Specify which, if any, movements are affected. The patient's normal range may be tested with reference to mobility of the unaffected arm and shoulder.

If doing exercises: Reinforce exercises learned in hospital and if necessary hand out new exercise sheets.

Scar acceptance: Assess if the patient is able to look at her scar and her feelings when she does so.

Prosthesis: Establish if the patient has and uses a temporary or semi-permanent prosthesis, and if it is satisfactory.

Bra: Assess, if available bra is adequate for holding a prosthesis.

Clothes: Assess if any problems with clothes such as those with low cut revealing necklines, or swimming costumes.

Section 3. Key Relationships

If relevant, husband or partner

Question samples (only if information not gained already)

How has your husband/partner felt about your operation?
Has he helped you?
What sort of things has he done? Have you had any help in the house?
Have things changed in any way between you?
Do you think he understands you?
What about the physical side of marriage?
Is that important to you?
What about your husband?

(If relevant):

Have you made love since your operation?
How did you feel then?
Has he looked at your scar? How does he feel about it?

(Family, children and adults)

Can we talk a little about the family?
Who else is close to you in the family?
Has he/she helped you?

(Support group/counsellor)

Were you given any information about support groups for people who have had breast cancer?
Have you been to a support group?
Was it helpful? In what ways was it helpful?

(Peer group/fellow patients):

Have you had much support from other patients?
In what ways have they been helpful?
Have you seen any of them since you came home?

Section 4. Interaction with Health Care Team since leaving hospital

Clarify number of interactions and in what ways the patient found them helpful or unhelpful.

Section 5. Social Adjustment

How are you managing here? Are there any problems about the house?
Can you manage the chores?

(If relevant)

What about work? Are you thinking of going back?
Are there any money problems?
What about your social life? What sort of things are you doing?
Do you feel that you are getting back to normal - perhaps seeing friends again?

Section 6. Psychological Adjustment

Recent stressful events. The patient's view of anything that has affected her adversely to do with herself, friends, family, domestic, or work situation since leaving hospital.

Ratings: When monitoring the patient's emotional state, ratings are given for key symptoms:

None - symptoms not present
Slight amount
Moderate amount
Severe amount

Anxiety

In order to rate an anxiety state, as well as evidence of an anxious mind four of the following symptoms need to have been present and pervasive for at least 50% of the time and need to have lasted about four weeks.

Symptoms:

1. Tension
2. Irritability
3. Panic feelings
4. Lack of energy
5. Impaired concentration
6. Sleep disturbance

Tension is a state accompanied by physical symptoms, such as headaches, palpitations, indigestion, diarrhoea, frequency of micturition, sweating, lack of appetite.

Questioning on sleep disturbance should include clarification about initial, middle, or late insomnia (early waking). The latter can be a sign of depression.

Rating of sleep:

Mild loss - 1 hour lost

Moderate loss - over 1 and up to 3 hours lost

Severe loss - over 3 hours lost

Question examples (general, anxious mood)

Most people tend to worry a bit, do you find that you do?

(specific)

What sort of things would you worry about? How long did these worries last?

(concentration)

Could you/can you put these worries out of your mind?

(sleep disturbance)

How have you been sleeping?

Can you get off to sleep at night?

When do you wake up?

Do you take anything to help you sleep?

(lack of energy)

Can you manage things at your usual pace?

Have you felt energetic or do you get tired easily?

Is the tiredness related to how much you do or is it general?

(panic feelings)

Have you had times when you suddenly felt frightened?

What sort of things did you notice?

What do you think brought it on?

(irritability)

Did you find you were at all edgy, strung up, easily irritated?

Tension

Do you get headaches at all?

Do you sometimes have a queasy tummy or sweating feelings?

Depression

In order to rate as a depressive illness as well as evidence of a depressed mood, four of the following symptoms need to have been present and pervasive for at least 50% of the time and need to have lasted about four weeks OR there is clear indication that the patient now has suicidal thoughts or a wish to be dead.

Coping

How do you feel you are managing?

Are you on top of things or do things get too much for you?

Suicidal thoughts

Did you ever feel so low that life wasn't worth living?

(If indicates 'yes')

Did you ever feel like doing something about it? Did you ever try?

How about now? Do you still feel like that?

Confiding relationship describes someone with whom the patient can speak freely about her emotional feelings, doubts, fears, hopes and general mood and who understands her.

Question example:

Is there anyone you can talk to who knows how you really feel?

Summary of Assessment

Outstanding problems of an acute or chronic nature need to be recorded.

Action taken or pending may refer to anything that is directed towards changing the situation, e.g. referrals to GP or other members of care team, e.g. hospital doctors, social worker, prosthesis fitter, BCMA.

Appendix 7

Examples of Discourse Analysis

Discourse analysis was used to test the hypothesis that the essence of social support was to maintain, enhance or help people make desired changes to their identities. Respondents' interview statements were analysed for evidence of identity marking and evidence of ways in which their statements were modified in relation to the actual or anticipated reactions of others (support or stress).

1 Identity marking in patients with breast cancer

Data was examined for statements in which respondents signalled their identities. The aspects of identity which they portrayed were constrained by the fact that the research explored their self perceptions at a time when they had breast cancer. While individuals' appraisals of what constituted the focal attributes of having breast cancer were not uniform, six broadly distinguishable dimensions were found. These constituting a significant proportion of the means by which respondents projected the identity of breast cancer sufferer. Since aim of the research was to explore the nature of social support, respondents' negative statements about their identities since the breast cancer diagnosis were of particular relevance. For example, most respondents contrasted their past feelings of security and permanence with their present uncertainty and awareness of their mortality.

It's a terrible feeling. You are going into the unknown. CG

Most respondents contrasted their previous identities as healthy people with present uncertainty about whether they would ever again be fully well. For most, their diagnosis was a great shock. For example,

It was 'completely out of the blue'. ... It was a terrible shock. JM

There was nothing wrong with me. I was working alright and suddenly somebody tells you you've got cancer. SL

Defending a healthy identity often involved strategies of denial, delay in reporting symptoms, normalising symptoms.

2 Making negative identity statements more positive in relation to others' actual or anticipated reactions-social support.

Data indicated ways in which respondents modified negative identity statements and made them more positive in relation to the actual or anticipated reactions of others, i.e. their social support. Frequencies of reported support for each aspect of identity were recorded. For example, all respondents expressed fears for their survival after their breast cancer diagnosis. These negative statements were modified by three types of support, (a) confiding, (b) upward comparisons, (c) downward comparisons.

(a) *Confiding*

The positive effects of confiding on identity were expressed in the following way.

Feelings of facing a threat with a significant other

We know how *we* are going to deal with it
She's *accepted me* as a friend and *everything with it*.

(b) *Upward comparisons*

The positive effects of upward comparisons on identity were expressed in the following way.

Having evidence in another's recovery, of the possibility of survival,

My sister had two mastectomies. *I do feel reassured* that *she has been through similar surgery*. AB

I know quite *a lot of people* who have had breast cancer and *made good recoveries*. *That's what I'm planning on doing*. HM

(c) *Downward comparisons*

The positive effects of downward comparisons on identity were expressed in the following way.

Having increased feelings of security in knowing that one is, in some way, better than someone else. Enhancing own identity.

I kept saying to myself 'You are not going for chemotherapy--'. 'You're not going for an implant. --Get a grip on yourself.'

I'm so lucky I'm on Tamoxifen because Y ... had the operation to have the breast removed.

Modifying identity statements in relation to anticipated reactions of others

Respondents modified negative identity statements, making them more positive in relation to anticipated as well as actual behaviour/attitudes of others. This was seen, for example, in the support they obtained from health visitors' perceived availability which reduced their feelings of uncertainty.

She's my lifeline. I know she's there. I suppose it's a bit like a kid with a night light. You know it's there if you want it. AF

It's nice just having someone who's in the background and you can call on them whenever you need them which is the important thing.

The data also indicated ways in which health visitors introduced negative statements about their professional identities and made them more positive in relation to actual or anticipated reactions of patients and colleagues. Health visitors reported four factors as being important to their professional identities, competence, achievement, doing a worthwhile job and being valued by clients. Their initial statements revealed that they perceived these aspects of their identities to be threatened by the newness of their role in breast cancer care.

I still don't feel anything like an expert and they still ask me things I can't answer. DL

E(patient) is actually a very capable lady. I can't say I feel it has been really good for her to have had me. If you really get stuck into this field you can speak with authority. RA

However, patients' comments often maintained and enhanced their professional identities.

I said to her (LB) very clearly 'Do you think it's of benefit me coming along? -- She said, 'Honestly I'll look forward to seeing you again.' JP

At the end of the interview she (HM) said something like she was amazed at how much better she felt or something that made me feel I had done something for her. DL

The visit was just at the right time. *'I'm so glad you've come'*, she said. RA

Making identity statements more negative in relation to others' actual or anticipated reactions-stress/strain statements.

Discourse analysis showed that respondents' identity statements sometimes became more negative in relation to actual or anticipated reactions of others (stress). Frequencies of such reported negative behaviours were recorded. For example, most respondents experienced negative or rejecting behaviour from someone in their social network whose own identity was threatened in some way by their breast cancer. There were four types of attitude/behaviour which did not maintain or enhance respondents' identities, as the following examples show.

Network member requiring support for own identity

My mother, sisters and brother *don't seem to have much time for me*. I don't think they can actually cope with it. They just don't talk about it. CB

He (husband) kept saying 'Don't worry.' *He just wished it wasn't happening. I didn't expect anything else.* AB

My mum *didn't come to visit me* when I was in hospital. Perhaps she couldn't cope. PK

One friend *hasn't spoken to me*. I was very hurt in the beginning about it. MW

One neighbour *hasn't been so friendly since I've been ill. We were very close.* She just sort of withdrew completely. AC

Network member not legitimating respondent's sick role.

It was a case of having to be okay. They've been saying things like, 'You're just skiving.' When you are feeling low you need a bit of understanding. AH

They (son and daughter) *won't do anything for you.* AF

Network member overprotective towards patient

I appreciate her (sister's) *efforts to keep me in check* but I feel back to normal now. AB

They all think I should sit around but it's not my nature. EH

Network member undermining patient's identity

She had no right to tell anybody. She was told in confidence. AF

Maintaining or enhancing identity in process of positive interaction (support)

Discourse analysis showed how respondents sought to maintain or enhance their identities by seeking affirmation (support) from others. Sometimes their projected identities were credible, sometimes challenged by their network members.

'Well woman' identity affirmed

When I first came out of hospital, my husband was good in practical ways. *Of course, I do it all now.* MM

When I'm at home, it's, 'Mum's home.' Really it's the best way. I'm getting on with it (housework). PK

'Well woman' identity challenged

I just want to put it behind me. The day I was out of hospital I was washing the floor in the kitchen. My husband and son were really angry. I realised myself it was stupid. JM

I think in some ways it's better to try and put it behind you and forget about it. *If you are going to a self help group it's continually bringing it back to your mind.*

'Normality' affirmed

At first I thought 'Oh gosh I've got something nobody else has got. Then you saw all the other people and there was nothing different about them at all. Then you accepted it. ES

'Normality' rejected

In hospital I went up to these two women. They said, 'Have you had your operation?' I said, 'Mine's a hiccup. I had mine five years ago. She said, 'I don't want to hear any more about it.'

Discourse analysis showed that identities were mutually constructed. This was especially evident in peer groups.

Reciprocal identity support

We went through all the tests together and jollied each other along. MM

Everyone shares a bit of themselves with someone else because you've all got the same thing. EM

You've got something you can give each other support about. MC

Appendix 8

Comparison of Health Visitors' scores in the 1st and 2nd Questionnaires (excludes experienced Health Visitor)

Average score on scale 0-5;
1st Questionnaire
Average score on scale 0-5;
2nd Questionnaire

